An Investigation of the Issues involved in Designing a Treatment Information Website for Cancer Patients

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Declaration

I declare that this sub-thesis is my own work and all sources have been acknowledged. I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma at any university, and that to the best of my knowledge does not contain any material previously published or written by another person except when due reference is made in the text.

Claire Bale

Abstract

The global prevalence of cancer is increasing rapidly, with virtually everyone touched by the disease at some point in life. Medical advances mean, however, that in comparison, mortality rates are decreasing. This means that there are more people living with cancer than ever before.

Not only are cancer treatments improving but they are also diversifying. More treatment options mean more choice, and cancer patients are now in the novel position of having important decisions to make about their care, and the type of treatment they want. However, evidence suggests that many cancer patients are not fully equipped to make these decisions. Patient education resources to address this problem are urgently required.

This thesis proposes the Internet as the appropriate medium, and a treatment information website as a viable solution. It also highlights a number of issues that must be considered when designing online health information sources. These include what kind of people are seeking health information, what types of information they want, why they feel the need for additional information, and the potential impacts that knowledge gained from the Internet can have on patients. In addition, a review of current resources is presented to explain where the gaps in information lie. This research was used to inform and aid the design of the prototype website: cancer treatment made clear.

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Chapter 1: Introduction

Background

Cancer is the term used to describe the diverse group of diseases that arise via the uncontrolled growth and division of abnormal cells. These abnormal cells may then invade and destroy healthy tissues, and can migrate to new locations within the body using the bloodstream or lymphatic system (The Senate Community Affairs References Committee, 2005).

The prevalence of cancer is increasing rapidly, partially due to the ageing populations in developed nations. In Australia, the number of new cancer diagnoses rose by 36% between 1991 and 2001, compared to a population increase of 12.3%. Currently a third of all men and a quarter of all women will be diagnosed with cancer before the age of 75 (McAvoy, Elwood & Staples, 2005). However, over the last decade cancer deaths in Australia have actually marginally declined by 1.9 per year (McAvoy et al, 2005).

What does this mean?

Although cancer incidence has increased considerably, detection, treatment and survival rates have improved at an even greater rate. Cancer medicine is amongst the most dynamic and well-supported areas of research. Just twenty-five years ago, the frontline treatments for cancer consisted of surgery and radiotherapy. Now we can add chemotherapy, hormone therapy, immunotherapy, diagnostic imaging and targeted biological therapies to an ever-expanding list (Souhami & Tobias, 2005). This means that cancer medicine is now a truly multidisciplinary practice, with patient involvement and choice becoming a major part of the cancer journey:

> From that moment on, my treatment became a medical collaboration. Previously I had thought of medicine as being something practiced by individual doctors on individual patients. The doctor was all-knowing and all-powerful, the patient was helpless. But it was beginning to dawn on me that there was nothing wrong with seeking a cure from a

> combination of people and sources, and that the patient was as important as the doctor.
>
> (Armstrong, 2000, p90)

In a 2005 report, a general consensus was reached for cancer care to become more patient-centred rather than disease-centred. Patients were expressing a desire for physicians who were willing to discuss their treatment options, to enable them to make informed treatment decisions (The Senate Community Affairs References Committee, 2005). Many have echoed this need for better-informed patients:

> As I reflect on the cancer journey, you have raised the important issue of how do people win the lottery. At a whole-of system level, we have a couple of options: one is to change the way we deliver health care; the other, in which I believe we can invest substantially, is to have better informed patients. That is to have accessible information specific to each cancer available to people so that they can ensure that the care they are getting is genuinely interdisciplinary...is timely and is credible. We need to complement any change to the health system with ensuring that health consumers themselves are adequately informed - not only the person with cancer because the effect does not finish there, but the people around them: their family and friends.
>
> (Professor Currow, quoted in
> The Senate Community Affairs References Committee, 2005, p126)

Problem

However, despite calls for adequate information to be provided, cancer patients still do not have access to sufficiently accurate and understandable information about their treatment options to make informed treatment decisions. As cancer diagnoses increase, and the range of treatment options expand, this problem will only escalate. Healthcare providers, particularly general practitioners often lack the time, the knowledge, or the skills to present these options to patients. Currently available information resources for cancer patients neglect treatment-specific information, including how treatments work, tending to focus more upon emotional support and

side effects. The resulting deficit in accessible information regarding cancer treatments suggests that many patients are unaware of their options and therefore not receiving the desired standards of care. In particular, there is a lack of information on the Internet, a resource which is rapidly becoming the preferred information source of many in the developed world.

Purpose

The purpose of this thesis is to propose and design a prototype website to explain *how* cancer treatments work.

Research questions

This thesis has three major questions:

1. What evidence exists to support a web-based information resource?
2. What kind of information do cancer patients need about treatments?
3. How can cancer treatment information be presented on a web site?

Overview of Method

Considering each of the research questions:

1. What evidence exists to support a web-based information resource?

A review of current literature concerning the "need" for cancer treatment information for patients was undertaken. This question raised a whole host of other issues, which are also discussed.

Issues addressed include:

- What is the potential impact of providing treatment information on patients and health care?
- Is there a desire for treatment information among cancer patients?
- Is the Internet an appropriate medium for providing treatment information?
- Who would make use of an online cancer treatment information resource?

2. What kind of information do cancer patients need about treatments?

Patient education about how treatments work may be beneficial for health care, but to provide a resource that patients would actually use means finding out what they want to know, and the information areas they feel are currently neglected. A review of the literature concerning cancer patient desires was carried out to respond to two particular questions.

- What type of treatment information do cancer patients want?
- What current resources offering cancer treatment information are available online?

The review contains a survey of a variety of currently available cancer Internet resources, including charitable sites, government (healthcare) sites, and private sites. The content and quality of cancer treatment information was assessed.

3. How can cancer treatment information be presented on a web site?

The information gathered in attempting to answer the previous questions helped shape both the content and the organisation of the proposed resource. A structural plan of the cancer treatment explanation website was subsequently suggested. A prototype version of this site was then developed.

Significance of study

This study is of significance to those considering the provision of a resource of this kind, and could represent a blueprint for a suitable website to address this problem.

Limitations

Due to time constraints, only certain aspects of the website could be developed. However the areas chosen for development were selected to give the best possible representation of the proposed site. A second major limitation of the website is that it is only available in English; this obviously excludes many patients from the content and should be addressed if the site were to be made available on the Internet.

Overview of the thesis

In this chapter, a brief outline of the background problem and the proposed solution are addressed. The main focus of the thesis is stated. The limitations are described and potential evaluation questions are also suggested.

Chapter 2 comprises a literature review examining the needs and desires of cancer patients, and how important and effective patient education is in healthcare. It also contains a review of the current online cancer information resources available to patients.

Chapter 3 outlines the methods used to design and construct the website, and will show which parts were chosen for development and explain the reasons why.

Chapter 4 is the prototype website on CD.

Chapter 5 contains a brief summary of the conclusions.

Chapter 2: Literature Review

The "C" Word

Cancer has become the modern equivalent of the plague, responsible for one in every four deaths in the US (Jemal, Murray, Ward, Samuels, Tiwari et al, 2005; Jemal, Siegel, Ward, Murray, Xu et al, 2007). The disease does in some way touch everyone, with over 200,000 new cases per year expected of prostate cancer alone (Table 1). However, despite cancer's high public profile and prevalence, most people only have a hazy idea of what cancer is and how it is treated.

Estimated new cases					
Males			Females		
Prostate	218, 890	29%	Breast	178, 430	26%
Lung & bronchus	114, 760	15%	Lung & bronchus	98, 620	15%
Colon & rectum	79, 130	10%	Colon & rectum	74, 630	11%
Urinary bladder	50, 040	7%	Uterine corpus	39, 080	6%
Non-Hodgkins lymphoma	34, 200	4%	Non-Hodgkins lymphoma	28, 990	4%
Melanoma of the skin	33, 910	4%	Melanoma of the skin	26, 030	4%
Kidney & renal pelvis	31, 590	4%	Thyroid	25, 480	4%
Leukaemia	24, 800	3%	Ovary	22, 430	3%
Oral cavity & pharynx	24, 180	3%	Kidney & renal pelvis	19, 600	3%
Pancreas	18, 830	2%	Leukaemia	19, 440	3%
All sites	**765, 860**	**100%**	**All sites**	**678, 060**	**100%**

Table 1: Ten leading cancer types for estimated new cancer cases by sex, US, 2007

(adapted from Jemal *et al* , 2007; p47)

The high prevalence of cancer means that the public perception of cancer is generally pessimistic with much of the focus on failed treatment and recurrence. To many, a cancer diagnosis means probable death, despite the fact that death rates have been declining by 0.5%-1.5% per year since the 1990s (Donovan, Carter & Byrne, 2006). The comparison of cancer incidence and mortality is shown in Figure 1.

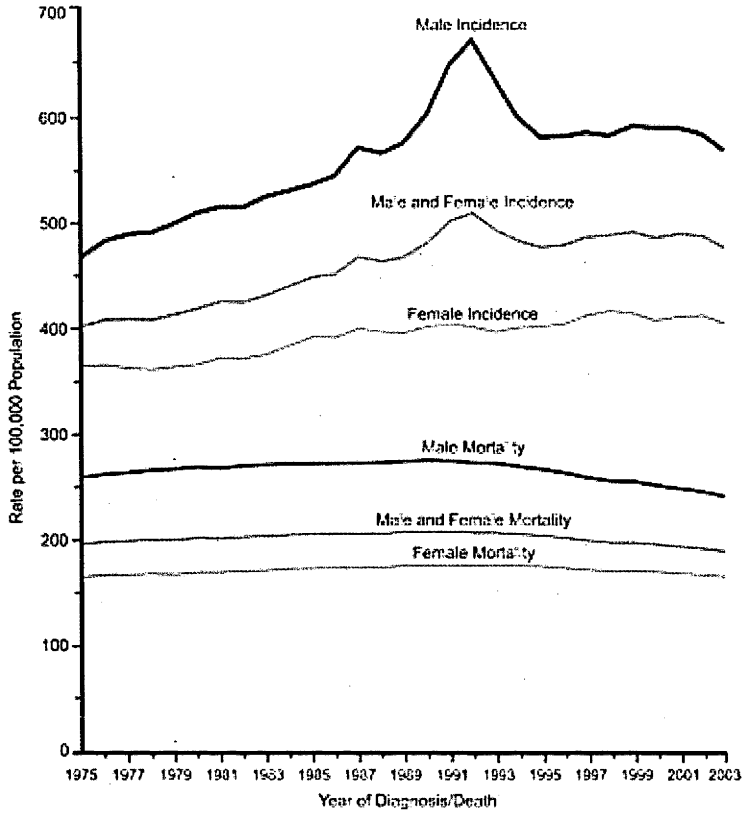

Figure 1: Annual age-adjusted cancer incidence and death rates for all sites, by sex, US, 1975 to 2003 (Jemal et al, 2007; p51).

A patient in Ziebland's 2004 study epitomised this bleak outlook: "he told me I had inflammatory breast cancer. All I heard was cancer and I held his hand and I just couldn't take it in" (p1787). A study looking at the perceptions of cancer compared to other serious medical conditions including cardiovascular and kidney diseases also highlighted an underlying pessimism (Cohen, 1982). Most subjects wrongly identified cancer as equivalent to or more serious than the other conditions.

Another study looked at the psychological impact of testicular cancer diagnosis on patients during the 1980s (Moynihan, Peckham, & Kurtz, 1988). At this time, testicular tumours were on the increase and becoming the most common neoplasm in young men between the ages of 20-34. However, due to improvements in treatment (mainly chemotherapy), the cure rate had also risen to over 90%. Despite this positive prognosis, these cancer patients still had high levels of psychological morbidity (anxiety and depression) following diagnosis.

The distorted image of cancer is, in part, attributable to the media. The general public rely heavily on the mass media for health news and warnings, even more so than on healthcare providers, family, friends or the Internet (Hofstetter, Schultze, and Mulvihill, 1992; Donovan, Carter & Byrne, 2006). However, cancer journalism is typically sensationalised, which may exacerbate these fears. It is often filled with inconsistencies and contradictions, and uses highly emotive language. All this contributes to the exacerbation of the public fear of cancer, and reinforces the despair many experience upon diagnosis as an appropriate reaction (Clarke 1992; Clarke & Everest, 2006).

For instance, an article that appeared in the British broadsheet newspaper *The Times* earlier this year reported on relative cancer risk:

> A study of more than 30,000 women who had gone through the menopause found that those who used HRT but had not been on the pill were 67% more likely to have developed breast tumours than women who had used neither. Those who used both were at 145% greater risk.
>
> (Dobson, March 25, 2007)

The use of statistics is emotive and gives a very dramatic impression of the risks associated with using either HRT and/or the contraceptive pill – a huge proportion of the female population do. However, it misleads the reader into believing that a 145% increase must mean a significant risk, when in fact the actual risk is still very low – and other risk factors such as smoking, being overweight, or diet are arguably much more important.

However, the media can also raise the public's hopes and expectations regarding cancer treatments. In an analysis of Australian cancer media sources, 75% appeared to bear a positive message such as promising new treatments, ways to reduce risks and reduced side effects of treatments (Donovan et al, 2006).

In a study by Niederdeppe and Levy (2007) into the public's fatalistic beliefs about cancer prevention, 47% of 6300 adults interviewed agreed with the statement; "it seems like almost everything causes cancer".

These negative perceptions of cancer make communications between doctors and patients more difficult, and patients less willing to discuss their treatment. Many cancer patients may be subsequently prescribed drugs and assigned to treatment programs with a very limited understanding of either what is wrong with them, or how their treatment will combat this.

In a study conducted by Mackillop, Stewart, Ginsburg, & Stewart (1988), cancer patients were asked about their perceptions about their disease and its treatment. One third of the patients who had a metastatic disease thought that their cancer was localised, and 40 of the 48 patients receiving palliative care had an unrealistically high perception of the chance that their treatment would extend their lives. A high proportion of the cancer patients had skewed impressions of both their disease and its therapy, but perhaps the most concerning aspect was the failure of their physician to notice their misconceptions.

A more recent study of doctor-patient relationships (Quirt, Mackillop, Ginsburg, Sheldon, Brundage et al, 1997) corroborated these findings. Lung cancer patients and their doctors were interviewed about the extent of the disease, and the intentions of the treatment. In most cases (63%) the patients understood the extent of their disease, and the majority also grasped the intent of their treatment. However, almost a third of patients being treated palliatively thought they were being treated with curative intent, and 10% of patients did not know the intent of their treatment. As a result many of the patients involved in this study made important decisions regarding their treatment options despite having an incomplete understanding of their situation.

Research has also indicated that women who developed emotional problems such as anxiety or depression after mastectomy are very unlikely to seek help from their physician (Maguire, Lee, Bevington, Kuchman, Crabtree et al, 1978). In the study, those who did seek help were generally dissatisfied with the advice and support they received. The doctors involved were interviewed, and seemed to assume that patients would come forward without any encouragement if they were experiencing problems. These studies raise issues concerning the doctor-patient relationship, and question how attuned doctors are with their patients informational and emotional needs.

Summary

On the whole, cancer survival rates are better than ever before. This is due to our improved understanding of the disease and better, more varied treatment options. However, public understanding of cancer and more specifically, its treatments is confused. The media play a large part in the confusion, sensationalising new breakthroughs as well as scaremongering over risks and statistics. The result of which is that many cancer patients are unaware of their disease state, their treatment options, their treatment intent, and their chances of survival. Clearly patient education for cancer patients is required to address this state of confusion.

What are the benefits of patient education?

Patient compliance

There has been very little research done into cancer patient compliance in comparison with other diseases. This could be because compliance is not a major problem in cancer therapy. Due to the real and perceived severity of the disease and the intensive nature of the treatment options (chemotherapy and radiotherapy), patients may be more inclined to follow doctors' orders. However, there is now a wider range of treatment types and strategies available than formerly. This emergence of new cancer therapies and the trend for using "cocktails" of different drugs may mean that choices arise for patients that had not been available before.

A study involving young men with cardiovascular disease suggested that compliance tends to be a problem in conditions where medication must be taken for extended periods and when the treatment elicits unpleasant side-effects (Hagstrom, Mattsson, & Skott, 2005). These are issues that may apply to many cancer treatments. Some studies into patient education and compliance in other diseases have proved encouraging. Another study demonstrated that nurse-guided education improved some aspects of heart failure patients self care, however compliance was not significantly improved (Gonzalez, Lupon, Herreros, Urrutia, Altimir, et al, 2005). Other studies also suggested that compliance tends to improve when the patient receives sufficient information about the treatment from their doctor (Hausman, 2001).

The biggest compliance issues in cancer remain screening and detection. For instance, regular cervical smears are estimated to prevent 80% of incidences of cervical cancer (Saul, 2001). But such screening procedures are often avoided due to women being unaware of the service, or nervousness and embarrassment about the procedure (Lovell, Kearns, & Friesen, 2007). In a survey of Indian women the most popular reason for non-compliance was that cervical smears are unnecessary unless you are presenting symptoms (see Table 2 below).

Reasons cited for non-attendance	Frequency of response (n=232)
I do not need any check up since I have no complaint	107 (46.1%)
I am scared of the tests	84 (36.2%)
My relative/neighbour had problem after they had the test	64 (27.6%)
Let fate/god decide my destiny	43 (27.6%)
I feel shy to be examined even by female doctors	35 (15.1%)
I cannot have any gynaecological problem since my menstrual period has stopped	31 (13.4%)
I feel shy to be examined by a male doctor	27 (11.6%)
I did not want to listen to anything about it	18 (7.8%)
I did not understand what it was all about	18 (7.8%)
I cannot afford treatment if cancer is detected	13 (5.6%)

Table 2: Responses of the women unwilling to have screening (Basu, Sarkar, Mukherjee, Ghoshal, Mittal, et al, 2006, p371).

This highlights a lack of understanding of the importance of early detection of cancer.

Informed decision-making

It is ultimately the right of the patient to make choices about their healthcare options. This is based upon the assumption that the patient can make better decisions for themselves than anyone else (Fagerlin, Lakhani, Lantz, Janz, Morrow et al, 2006). Some patients' treatment choices may be based upon different criteria than survival benefit, such as quality of life, expense or side effects (Brundage, Feldman-Stewart, Cosby, Gregg, Dixon et al, 2001). However, this presumes that the patient has a good understanding of all their treatment options, which is not always the case.

Fagerlin et al (2006) conducted a study into breast cancer patients' understanding of their surgical treatment options. They suggested that the majority of patients did not possess sufficient understanding to make an informed decision about surgical treatment. Less than half of patients knew that breast conserving surgery with radiation therapy, produces the same survival rates as mastectomy. There is also evidence of an increase in patients' desire for knowledge. A survey carried out in 2001 showed that more than 50% of Canadian cancer patients felt that their doctor did not supply them with sufficient information about their condition (Chen & Siu, 2001).

Involvement in their treatment decisions has also been shown to significantly reduce anxiety and depression in cancer patients (Williams, 1988). The patients in this study also generally expressed a desire to be part of the decision making process. Another study examined the effect of varying levels of involvement in their treatment decisions, and found that cancer patients experience anxiety when their doctor does not match their personal informational needs. Many patients do desire all the relevant information to take an active role in their health management; when their doctors do not supply them with this, they experience anxiety. Conversely some patients prefer not to know, and if their doctor tries to educate them and involve them this causes them anxiety. This study highlighted that different patients have different needs and expectations in terms of treatment information; failure to meet these needs causes distress and confusion (Gattellari, Butow & Tattersall, 2001, p1875).

In spite of the arguments for informed patient decision-making in cancer treatment, doctors are still very much in the driving seat when it comes to selecting the appropriate therapy. This was shown in a qualitative study of prostate cancer patients who were interviewed about their experiences of the treatment planning process (Cohen & Britten, 2003).

> The specialist decided whether the condition required active treatment or if a watchful waiting policy could be adopted. When active treatment was advocated, the patients felt that the clinician advanced their chosen option, mentioning other possibilities in order to explain their inappropriateness and to justify the preferred choice.
>
> (Cohen & Britten, 2003, p726).

At the time of diagnosis this approach seemed to be preferred and even desired by the patients.

> Most men felt that the directive role assumed by the clinician was appropriate and welcome. The treatment decision was perceived as a technical one, which required expertise and experience. The men expressed a high degree of trust and respect for the clinicians, as well as a hope that the professional would act virtuously and competently on the

patient's behalf.

(Cohen & Britten, 2003, p726).

Following a period of reflection, many of the subjects in the study felt that they would have preferred to play a more active role in the process, "Having had time to think things over, the interviewees felt that their needs had changed, which left them wanting to revisit the decision and the way that it was made" (Cohen & Britten, 2003, p728).

Informed decision-making is critical for improving quality of care. To make truly informed decisions patients must be given comprehensive and accurate information that is clear and unbiased to ensure that their preferences are based on fact and not misconception. Only when the patient understands the relative risks and benefits associated with each treatment option can they make a truly informed choice (Say & Thomson, 2003).

Improving quality of care

In 2003, a paper in the New England Journal of Medicine proposed that adults in the United States receive only 55% of the recommended care for their medical conditions (McGlynn, Asch, Adams, Keesey, Hicks et al, 2003). Patients often need to be assertive in their attitude to healthcare to receive full and appropriate treatment. The empowerment of patients to take responsibility for their treatment requires better patient education, including access to information resources about therapeutic options (Steinberg, 2003).

Reducing fear of cancer

Accurate knowledge of cancer is related to a reduced fear of cancer, and subsequently reduced psychological distress (Berman & Wandersman, 1991). People with a good understanding of cancer are less likely to misinterpret common symptoms as signs of cancer, and usually hold greater faith in cancer treatment strategies. This is significant, as a poor understanding is often associated with a tendency to avoid seeking medical treatment for cancer-related symptoms, either due to general ignorance, fear or distress. Denial may also be associated with fear, stemming from fear of what the symptoms may mean, or simply from ignorance of the importance of

early detection. One study found that more than 40% of patients at an oncology clinic delayed seeking medical diagnosis of their conditions for between 4 months and a year because they believed (or wanted?) their symptoms to be insignificant (Hackett, Cassem & Raker, 1973).

Improved chances of survival?

Studies have suggested that patients with a more positive attitude towards diagnosis and treatment of their cancer are significantly more likely to survive and be free from recurrence (Greer, 1988). Educating patients about their disease and their options will, it is hoped, mean a more positive and optimistic approach is adopted in terms of their treatment.

Patients who approach cancer with "fighting spirit" do seem to show the best recovery rates. These patients are also associated with having the greatest thirst for knowledge and information about their condition, with the aim of fighting it most effectively. Those who respond to diagnosis with a helpless/hopeless attitude are the most likely to succumb to the disease. Exactly how the mental attitude of cancer patients affects their survival is unclear. But, whatever the reasons, clearly changing people's attitudes towards cancer and the treatment of cancer, is desirable.

Summary

Having established that there is a deficit in the public and patient understanding of cancer and its treatment, the value of patient education must be reviewed.

In terms of patient compliance, adherence to treatment in cancer may be improved by educating patients. Education may also improve attendance for screening procedures, and the early diagnosis of cancer.

Informed decision-making could ensure the most appropriate treatment choices are made for every patient, taking into account their personal criteria. In addition, this may help minimise patient anxiety.

Together these aspects may improve the overall quality of cancer care. Additionally, making patients partners in their own healthcare will place more pressure on

healthcare providers to supply the best possible care and full range of options.

A greater understanding of cancer is generally associated with reduced fear of cancer; this could ultimately improve compliance, screening and early detection, as well as reducing fear and distress.

A combination of the factors listed above may serve to not only improve healthcare, but also patient attitudes. It has been suggested that patients with more positive outlooks upon their disease and its treatment are more likely to survive.

In considering the first research question: what evidence exists to support a web-based information resource? The inherent value of patient education supports the provision of information specifically for cancer patients. But, the characteristics of the Internet that recommends it as a suitable medium for this purpose must be considered.

The Internet as a tool in cancer patient education

1. The rise of interactive health communication (IHC)

In 1999 the US Government Department of Health and Human Services published, *Wired for health and well-being: the emergence of interactive health communication* (Eng & Gustafson, 1999). This document recognised the emergence of interactive communication (i.e. the Internet), and its potential impact on healthcare.

They identified the functions of interactive health communication which were to:

- relay information
- enable informed-decision making
- promote healthy behaviours
- promote peer information exchange and emotional support
- promote self-care
- manage demand for health services

The functions of IHC identified in the report are ultimately the same as the goals of patient education.

The report also addressed the various factors affecting the adoption of interactive communication in health care (Table 3).

Factors that impact the adoption of IHC	Barriers to widespread adoption of IHC
1. Increasing telecommunication and computing capacity	1.Health care provider resistance
2. Increasing computer literacy and access	2. Lack of financial incentives to change health care provider behaviour
3. Increasing consumer demand for health information and shared decision making	3. Lack of access to infrastructure and inability to utilise applications
4. Increasing emphasis on primary and secondary prevention	4. Substantial implementation and maintenance costs
5. Increasing trend to reduce cost of health care services	5. Lack of convincing data on effectiveness

Table 3: Factors affecting adoption of interactive health communication (IHC)

(Using information from Eng & Gustafson, 1999)

However, in the eight years since the report was published the factors driving IHC adoption have gained momentum; more people have computer skills and access than ever before, and consumer demand for health information and shared decision making is still rising. In contrast, the barriers to IHC adoption have been falling away. The influence of healthcare providers has lost some relevance; anyone can put health information on the Internet and anyone can access this – the support of healthcare providers is not required. The swing in these factors has resulted in a landslide towards the adoption of IHC. This has been reflected in the literature, with respondents in one survey identifying the Internet as the second place they would go (after their health care provider) if they had a "strong need" for cancer information (Treiman & Squiers, 2005).

Summary

There are many factors driving the adoption of the Internet as a major resource for health information including:

- increasing speed and access to the Internet
- increasing ability to use the Internet
- increasing demand for up-to-date health information resources
- increasing range of treatment options
- increasing consumerism in healthcare

The Internet also boasts a range of advantages that are unique to this mode of communication, and recommend it as a suitable means for conveying health information.

2. Advantages of internet-based health communication

But what distinguishes the Internet from print media or healthcare providers as the best communication tool for health information? Table 4 (below) highlights some of the capabilities of the Internet, which may be advantageous for this type of information resource.

New capacities	**Advantages**
Instantaneous interactivity	Immediate feedback can be provided through linked websites
Convenience	Computer-mediated communication eliminates time restrictions on access to material
Appeal	Young adults have reported greater preference for computer-delivered information than traditional print-based material
Flexibility	Users can choose what material they access, and when or how they access it
Individual tailoring	Information delivery can be individualised and tailored
Automated data collection	User information can be automatically collected
Openness of communication	Users interact with computers, rather than with other people, which means responses to sensitive question and willingness to explore sensitive issues tend to be more candid
Multimedia interfaces	Use of still and video graphics and recorded sound files reduces the literacy requirements for intervention and educational material

Table 4: Capacity of computer-mediated communication and advantages for preventative medicine and health sciences (adapted from Fotheringham, 2000, p.115)

The Internet is global. It allows patients to compare their treatment options not only within their own country, but also internationally (Ziebland, 2004). Internet sites are accessible anywhere. However, despite the lack of physical barriers on the Internet, there are still issues surrounding language barriers. Should all websites be available in translated forms?

Websites can be continually updated at relatively little cost and inconvenience – to provide a dynamic and up-to-date resource for consumers. This does not mean that all

websites are up-to-date; in fact many are not, with thousands of out-dated sites floating around on the Internet.

The Internet can be globally available, high speed, free to access and potentially available over 24 hours depending on the patient's situation. This means it can effectively provide access to health information and support on demand. This may be particularly pertinent in healthcare. Many of those seeking health information are scared and vulnerable. It is important for people to have access to credible information and support they want when they most need it. Ball and Lillis (2001) made the comment, "Today's consumers, many of whom are overworked, well-educated, and desperate to preserve their free time, expect the highest level of convenience from every industry they interface with" (p2). This sentiment was echoed by another patient from a different study:

> So many people have computers nowadays, you haven't actually got to leave your house, it doesn't matter how you're feeling. You don't even have to get dressed; you can just, you know, log on and you can get the information. Which I think is going to do absolutely nothing but help people.
>
> Patient (Ziebland, Chapple, Dumelow, Evans, Prinjha et al, 2004, p565).

The Internet also allows the protection of the privacy of the user who may be dealing with sensitive information and issues. In an analysis of an Amyotrophic Lateral Sclerosis (ALS) discussion group on the Internet between patients and caregivers, it was found that most of the posts revolved around support and emotions (Feenberg, Licht, Kane, Moran & Smith, 1996). There was open discussion of personal issues, including sexual issues such as the persistence of desire and the frustrations of the patients. Many suggested that the liberating anonymity of the Internet forum allowed this frankness, and this need for privacy seems to represent one of the most important advantages of the Internet to cancer patients.

> It's so personal because... it's your body, but you have to go somewhere. What better place to go than—well certainly in my circumstances, where I have a computer at home that I can switch on, in total privacy. I don't

> need to feel that I'm asking a dumb question. I don't need to feel that I have to ask all the right questions first time round.
>
> Patient (Ziebland *et al*, 2004, p565).

The use of networking technologies such as email and Internet discussion sites means that the logistical and social barriers between patients, and health care providers can be broken down. For instance, in an early study conducted by Brennan and Ripich (1994), a group of 26 AIDS patients were given computer access to a specifically designed network from their own homes. The network included three main functions, communication (between patients via email), information, and decision-support. The patients' usage was monitored over a period of six months, during which time they accessed the network over 8000 times, with private email emerging as the most popular function. Brennan and Ripich (1994) suggested that the email service reduced the feelings of isolation felt by the patients, and offered social support.

A unique feature of the Internet is the capacity for patients themselves to become the developers, and to actively participate in the information exchange and dissemination process. An example of this type of internet-mediated information exchange is the ALS (Amyotrophic Lateral Sclerosis) digest, a weekly e-newsletter set up and edited by one ALS patient, Bob Broedel. The ALS digest was started to "serve the world-wide ALS community", including patients, researchers, and caregivers as stated in the mission statement, and was made up of articles sent into Mr Broedel by subscribers. The emphasis of the newsletter was on the distribution and exchange of information regarding all aspects of ALS by the "ALS community" (Feenberg et al, 1996).

As technology improves the capacity to tailor health information to the individual through interactivity is becoming commonplace (Richards, Colman & Hollingsworth, 1998). This means that using the Internet for health advice is becoming a more individual experience. Only information specific to that patient is presented, which reduces confusion and unnecessary reading on the patients' part. Another advantage of interactivity in patient education is that using multimedia approaches including video, text, animation, graphics, pictures, graphs and audio, can appeal to a wider range of patients with different learning styles. This can be especially helpful for individuals who find learning from written information difficult, individuals with

lower literacy skills, or individuals with visual impairments (Jones, Nyhof-Young, Friedman & Catton, 2001; Richards et al, 1998). Interactivity is also a useful tool for improving the attention and understanding of the material (Evans & Gibbons, 2007).

Websites can also contain colour photographs, audio recordings and even video clips that do not require expensive hardware for the patient to view. Downloadable PDF files mean that high quality material can be delivered directly to the patient at minimal expense, whereas printing and distributing educational booklets is costly to produce, update and is often very inefficient (Richards et al, 1998). Also, once a website is up and running, updating and maintaining the site is relatively cheap and requires minimal time, effort or expertise.

Perhaps most importantly, the Internet is growing exponentially. According to internetworldstats.com (accessed 19/07/07), world Internet use has increased from 16 million users in 1995 to a staggering 1.154 billion users in 2007 – now accounting for almost 20% of the total world population. No other medium has access to such a huge audience.

Summary

The Internet possesses many attributes that make it a useful tool for patient education. It is global, timely, convenient, anonymous, flexible, interactive, multimedia, relatively cheap, and continuously growing. It also has a capacity for networking and patient-involvement that no other medium can provide.

The Internet does, however, have some limitations.

3. Limitations of internet-based health communication

Inaccurate information

In some cases information available to patients online may be incorrect, out-of-date or misleading (either purposefully or accidentally). This can have serious implications for their subsequent health care decisions. As in the previous example of Broedel's ALS digest, there is often no quality control of medical information, "Please be advised, the editor is not a medical doctor and the Digest is not peer reviewed" (disclaimer from the e-newsletter (Broedel, 2001)). Although this limitation of the digest is acknowledged in the disclaimer, it does not make up for the fact that inaccurate and misleading information could very easily be widely distributed. This type of information-sharing online can lead to the amplification of "fads" in medical treatment (Feenberg et al, 1996). This may encourage self-diagnosis, and even more dangerous, self-treatment, as more and more prescription drugs become available to buy through the Internet. For instance; searching for the term "Viagra" on Google, brings up a number of sites seemingly willing to sell it regardless of it being a prescription drug (Timmons, 2001).

In a 2003 study, it was found that 12% of patients who use the Internet to search for cancer-related information, end up buying unconventional medical therapies over the Internet (Metz, Devine, DeNittis, Jones, Hampshire et al, 2003). However, in the Pew Internet Online Health Search 2006, only 3% of US health searchers, or about 3 million adults, say they or someone they know has been seriously harmed by following advice or information they found online.

Damage to the patient-provider relationship

Many of the medical profession are wary of the availability of medical information on the Internet and what it may lead to. Fears that patients will demand more time from their physicians and confront them with reams of print-outs have been expressed, as well as concerns over the quality and accuracy of the available information (Nettleton, Burrows & O'Malley, 2005). Others have interpreted the reluctance of health professionals to embrace the Internet as a patient education tool as a symptom of their unwillingness to give up their position of power. Patient education (or

deprofessionalisation) "is associated with a demystification of medical expertise and increasing lay scepticism about the health professional" (Hardey, 1999, p821).

Issues of privacy, confidentiality and quality

Privacy is critical in healthcare; we all know about doctor-patient confidentiality. The Internet represents a potential spanner in the works. Patients may be unaware of the exploitative power of the web: entering their email address at a particular site could mean the address is leaked or sold, used as a spoof address, or even used in identity theft (Crippen, 2007). Every time you enter any personal details onto the Internet you take a risk, even on reputable sites. And when that information is personal health details, the potential consequences are severe. But are patients using the Internet aware of these risks?

Additionally, due to the huge volume of cancer information available already online, a new website may get lost in the sea of pre-existing resources. Because there is no policing of the content of Internet sites, users are wary that information they see online may not be reliable (Ziebland, 2004; Seale, Charteris-Black, and Ziebland, 2006). A significant number of patients have reported difficulty in locating "quality" information online (Salo, Perez, Lavery, Malankar, Borenstein et al, 2004).

Sometimes print media are more effective. One investigation compared the efficacy of the web and print media for promoting physical activity among adolescent girls (Marks, Campbell, Ward, Ribisi, Wildemuth et al, 2006). To their surprise, after a two-week period, the girls who were given the printed workbook expressed greater intentions for increasing their physical activity than those who used the interactive web-resource. Their findings implied that traditional printed media could be more effective for patient education. Perhaps printed publications elicit greater patient trust than online information.

Many medical resources available online are intended to be used exclusively by researchers (journal articles), or health care professionals. However, patients now have access to these resources as well. Without the necessary medical knowledge or experience, patients may form unrealistic ideas about their condition or their treatment options (Richards et al, 1998).

Finally, we must not forget that technology itself is fallible. Links may be broken, sites may not work properly in a particular server, and errors are inevitable. This can be intensely frustrating for the user, but as the Internet and sites improve, these errors are becoming less frequent.

Inequities in Internet access and computer literacy

Drawbacks specific to a website providing cancer-drug information include issues concerning the target population. Providing information online presumes that the majority of the target audience (i.e. cancer patients) have Internet access. Visitors of online health information resources tend to have higher incomes, higher education levels, and are most likely to be white (Gilmour, 2007). Another concern is the potential existence of an "inverse information law", which suggests that those who need information the most are those that are least likely to have access to the necessary technology (Ziebland et al, 2004).

However, in terms of wealth, cancer is predominantly a disease of the western world, with one in three westerners likely to develop the disease within their lifetime. In developing countries cancer is less of a problem due to the lower life expectancies (cancer is a condition that usually develops later in life). But, the fact that most cancer patients are over 60 presents a problem. Studies have shown that this generation are much less likely to be regular Internet users or even have access to the Internet, than younger people (Metz et al, 2003). Will using a website to convey this information mean that the major demographic affected by cancer is not reached?

Barrier Cited for Non-Use	Frequency (% of patients)
No computer access	53
Lack of interest	49
Not knowing how to use computer or internet	39
Not knowing cancer information on the internet	20
Cost	18

Table 5. Barriers to Internet use

(Helft, Eckles, Johnson-Calley & Daugherty, 2005, p4857).

Helft et al (2005) showed that the greatest obstacle to Internet use for cancer patients at an urban county hospital was lack of access (Table 5). However, computer literacy and the perception of the Internet as a cancer information resource were also significant factors, which may be indicative of the typical age of most cancer patients. Importantly, these three issues are likely to die out in the future as the Internet becomes more ubiquitous and computer literacy continues to increase. The other major factor, a lack of interest, is less likely to change.

Ethnicity had also been suggested as a factor in Internet availability and use. However, a study showed that African-Americans actually rely more heavily on the Internet as an informational resource than white-Americans (Fox, 2006). The popularity of the Internet amongst African-Americans is also rising with two million over the age of 30 accessing the Internet for the first time in the year 2000 (Spooner & Rainie, 2000). These findings may indicate a lack of access to other health resources in African-American communities (Cline & Haynes, 2001).

Summary

By placing information on the Internet you inevitably exclude a certain section of the population, whether through lack of Internet access or computer literacy. However, with the exponential rise of the web, these issues are becoming less and less important.

Other more technical problems such as violations of privacy and technology errors are less of a concern. Issues of privacy are certainly important, but in the context of simply providing information, this should not present a serious concern as no personal information would be necessary for access to a cancer treatment site. Errors in the software supporting the Internet are also on the decline as the Internet continues to improve.

Perhaps the most pertinent factors that should be considered when preparing health information for a website are issues of content quality and accuracy, and the effect the information may have on the doctor-patient relationship.

Overwhelming evidence exists to support a web-based information resource, but for such a resource to be viable this must be a need perceived by the patients themselves. So, having established the Internet as a suitable medium for cancer patient education, the desire for cancer information must be assessed.

4. Public desire for cancer information online

"The World Wide Web has blown away the walls and doors of medical libraries, which once shielded medical knowledge from the public gaze. Members of the public can now have access to almost all the information that professionals have" (Muir Gray & de Lusignan, 1999, p1476).

Although the evidence supports the need for better cancer patient education, and the Internet provides the perfect means for conveying it, do cancer patients actually want to be educated? According to the old adage "you can take a horse to water, but you can't make it drink" – there must be a thirst for knowledge; otherwise the proposed resource will be useless.

The management of cancer has evolved considerably over the last ten years, and this development is set to continue. Patients appear to want to be more involved in decision-making, but a doctor's time is more limited than ever. Additionally, the range of available treatment options is ever expanding, making it increasingly difficult for doctors to ensure patient understanding (Sabel, Strecher, Schwartz, Wang, Karimipour et al, 2004).

Since patient decision-making in cancer treatment has become more common, educational "decision aids" have been developed and used to some extent. One study examined the use of an interactive CD-ROM by patients with breast cancer (Molenaar, Sprangers, Oort, Rutgers, Luiten et al, 2007). Ninety two percent of the patients in the study used the decision aid, and most patients used it for more than one hour, during which time they searched for information on a number of different topics. The most popular topics searched were the medical and treatment-related sections, indicating a strong need for this type of information.

In terms of the Internet, health information is a popular search topic. The Pew Internet and American Life Project Report, published in 2003 (Fox & Fallows), claimed that 80% of adult Internet users in the U.S. have searched for health-related information online. This included 63% who searched for information regarding a particular medical condition. One user commented that, "...information available on the internet takes the mystery out of illness and gives the patient a sense of power over his/her condition" (Fox & Fallows, 2003, p7).

Sabel et al (2004) reported that almost 40% of patients with melanoma used the Internet independently to search for additional information about their condition. Patients are also routinely asking their healthcare providers about material they have read on the internet, or asking about internet information sources they should use (Ferguson 2000; 2002).

Additionally, monthly accesses to the cancer information website Oncolink (www.oncolink.org) have increased hugely in recent years. In 1994, they received around 30,000 hits per month, a figure which rose to 9.5 million per month by 2004 (Martin, 2004). A subsequent study by Helft et al (2005) reported that 44% of cancer patients without Internet access would read more about their cancer if they had a way to use the Internet. Salo et al (2004) carried out a study designed to assess the public desire for health care information online. They surveyed a random selection of 328 patients visiting an inner city hospital emergency department in New Jersey for their opinions (Table 6).

	All patients	Patients with Internet access	Patients who had searched the Internet for medical information
Not interested	24%	14%	8%
Somewhat interested	15%	15%	13%
Interested	29%	32%	33%
Very interested	30%	39%	47%
Total	100%	100%	100%

Table 6: Patient interest in the provision of medical web sites

(adapted from Salo et al, 2004, p297).

This study showed that less than half of people visiting an inner city New Jersey hospital have Internet access, and yet 59% of all patients said they were either interested or very interested in being provided with medical websites concerning their condition. This meant that many interested patients did not even have access to the Internet. This may indicate that they were planning on getting Internet access in the future, or would have friends or relatives to search for them.

In a study by Edgar, Greenberg, and Remmer (2002), 27 cancer patients and 15 family members were provided with internet lessons to help them search for and

evaluate cancer information available online. The sample included subjects ranging in age from 20 to 70. Of the subjects, 43% expressed a strong interest in learning how to use the Internet, 25% were somewhat interested, 25% felt they already knew how, and only 8% had no interest at all. In addition, 94% of the sample group said that they felt it was either very or somewhat important to use the Internet to access information on cancer and its treatment. Although not all cancer patients actively seek information regarding their disease online, the availability of the information on the Internet makes this a choice, and is readily available should they feel the need to question whether the treatments they are being offered are optimal (Ziebland, 2004).

Summary

A hugely important question to ask when it comes to providing health information online is whether the public and patients desire this type of resource. From previous work it appears that online health information is a public need, and that cancer patients desire an online cancer information resource. In support of this, a survey reported that American oncologists estimated that approximately 30% of their cancer patients actively use the Internet to research their condition online (Helft et al, 2005). Using a meta-analysis of 24 published surveys it was estimated that around 39% of cancer patients, or 2.3 million people with cancer, are currently Internet users (Eysenbach, 2003). Taken together these figures suggest that a substantial chunk of the cancer patient community with access to the Internet use it to research their disease.

In considering research question 1: what evidence exists to support a web-based information resource? The previous literature supports the proposal of an Internet resource for cancer patients; patient education is required, the Internet is the most obvious tool, and many patients already use web sites to find health information. Additionally, in all three of these aspects growth is expected as treatment options diversify, the World Wide Web continues to grow, and the number of people with access expands.

Next, research question 2 will be addressed: what kind of information do cancer patients need about treatments? First, given the importance of the Internet to patients, is it possible to describe the characteristics of patients who dominate Internet use?

5. Who searches for health information online?

According to an Online Health Search (Fox, 2006), women are more likely than men to look for health information online. This is supported by other recent studies, which looked into gender differences in health-information seeking on the Internet (Seale et al, 2006, Sillence, Briggs, Harris, & Fishwick, 2007c). These authors found that women are more prolific in terms of internet use, but they also found that men and women are interested in different aspects; men are more interested in biomedical information on their cancer, whereas women look more for emotional support.

Women's more communicative role was also demonstrated in a study examining the use of message boards for patients of two gender specific cancers: breast cancer (98.5% are female), and prostate cancer (100% male). Despite numbers of new diagnoses of breast and prostate cancers being almost identical, there was almost double the number of posts on the breast cancer message board. On the breast cancer message boards, 87% of messages came directly from the survivors themselves, compared to only 54% on the prostate cancer boards. The majority of the remaining messages (46%) consisted of the wives of survivors (Blank & Adams-Blodnieks, 2007).

The Online Health Search (Fox, 2006) shows that more than half of the people searching for health information online are looking on behalf of someone else, usually a spouse, family member or friend. Seale et al also observed this; "Several relatives and friends who had access to the Internet began sending us helpful printouts from web sites listing treatments" (2006, p2584).

However, other studies have contradicted this including that of Sillence et al (2007c) who suggested that the majority of people who search online for health advice are looking for themselves. Around 20% claim to be looking for themselves *and* others, and 15% just for others.

Table 7 shows that many cancer patients receive cancer information from friends or family members who have searched online. The highest proportion of patients who received information in this way were prostate cancer patients. Prostate cancer being an exclusively male cancer, this may support the idea that men are less likely to search for cancer information, and that women in their role as caregivers search on

their behalf.

			Number (%) of respondents with access to Internet cancer information		
Site of cancer	Number of respondents	Mean (range) age at interview	Accessed by self	Accessed by friend/family	Total
Breast	37	44 (19-75)	17 (46)	2 (5)	19 (51)
Bowel	31	58 (33-80)	5 (16)	3 (10)	8 (26)
Cervix	21	40 (23-51)	6 (29)	4 (19)	10 (48)
Prostate	49	62 (51-83)	10 (20)	7 (14)	17 (35)
Testes	37	39 (21-55)	17 (46)	5 (14)	22 (59)

Table 7: Reported use of the Internet for cancer information and support in patients interviewed with cancer diagnosed since 1992 (adapted from Ziebland et al, 2004, p565).

Other studies have suggested that it is often the spouse of the cancer patient who feels in need of additional information. Salander and Spetz (2002) performed a survey of 25 malignant glioma patients and their spouses, and found that spouses were usually less satisfied with the medical information provided than the patient. Clearly the need for information of partners and spouses of cancer patients should be considered as well as those of the cancer patient (Bar-Tal, Barnoy & Zisser, 2005).

Certain cancer types may require more information, or be more regularly searched for than others. For instance, it has been reported that people suffering from stigmatised illness are more likely to search for health information online than those with more socially acceptable diseases (Berger, Wagner & Baker, 2005). A stigmatised illness can be defined as one that involves shame or embarrassment to the patient due to the perception of the condition in society. In terms of cancer, some types may be stigmatised, whereas others are not. Lung cancer patients often feel isolated due to the public perception that they have brought their condition upon themselves through smoking – whether they did or not. One patient commented, "Because we don't understand it, because there's no way of understanding cancer. Um, it's something that grows within certain people and there's something disgusting about it" (Chapple, Ziebland, & McPherson, 2004, p404). This stigmatisation of cancer may also discourage patients from seeking support (Chapple et al, 2004).

Age is a factor that strongly influences a patient's likelihood to search for information

online. In a study of patients visiting a variety of different radiation oncology institutions, it was found that 29% of patients had used the Internet to find cancer-related information (Metz et al, 2003). Although, the mean age of the patients was 64, it was the younger patients who were much more likely to use the Internet.

Summary

Reports suggest that the main users of the Internet for health advice are: patients, friends and/or family of patients, and spouses of patients. Many of these users are probably of a younger generation who are more comfortable using computers and the Internet. A greater proportion of Internet health seekers are also thought to be women. This may be related to the traditional role of women as caretakers of family health.

With a better idea of the types of people currently using the Internet for cancer information, an appreciation of the types of information they are looking for is required.

6. What type of information do they search for?

The Pew Report (2003) shows that people seem to be primarily interested in information regarding a specific condition, and secondarily in particular treatments or procedures. This suggests that people do tend to look for "facts" on the Internet, and medical explanations (Table 8).

Health topic	Internet users who have searched for information		
	Men	Women	Both
Specific disease or medical problem	54%	72%	63%
Certain medical treatment or procedure	40%	54%	47%
Diet, nutrition, vitamins, or nutritional supplements	39%	48%	44%
Exercise or fitness	34%	38%	36%
Prescription or over-the-counter drugs	29%	38%	34%
Alternative treatments or medicines	23%	33%	28%
Health insurance	22%	29%	25%

Table 8: Health topics searched for online (information taken from Fox & Fallows, 2003).

Figure 2 shows that emergency department patients appear to go online predominantly to research diseases, followed by various treatment options (Salo et al, 2004).

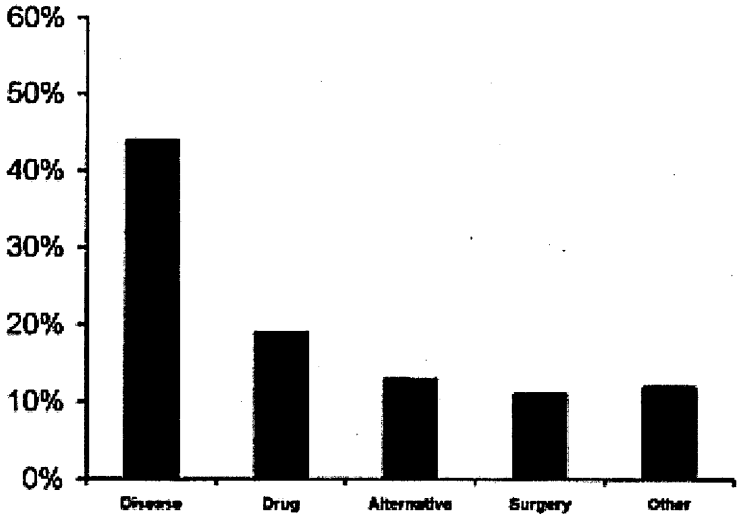

Figure 2: Information types searched for online by emergency department patients (Salo et al, 2004, p296).

These results may not be that applicable to cancer due to the disparity in the situations

of emergency department patients and cancer patients. However, this information does indicate a universal desire in patients to *understand*, both their medical condition and the treatment options and alternatives available to them.

In a study of prostate and breast cancer patients (Rosmovits & Ziebland, 2004), a diverse range of informational needs was expressed (Table 9). This included up to date biomedical information about cancer treatments as well as suggestions for advice on "how to talk to children about cancer" at the other end of the spectrum. There seems to be a real desire for information of all varieties, not just one specific type. This may be a symptom of the total confusion and suspicion surrounding cancer, and a lack of information provided by physicians.

Information need
• 24h, 7-day access • Experiential information from other patients • Information to meet different needs at different stages of illness • Details of local support organisations • Up to date information about cancer treatments • Explanation of the role of specialist nurses • Suggested questions to ask health professionals • Information about complementary approaches • Practical information about what is needed in hospital • Information about recovery times • Information about all treatment options and side effects • Information about financial help and benefits • Resources for teenage children whose parents have cancer • Suggestions about how to talk to children about cancer • Access for those without Internet connections

Table 9: Information needs described by cancer patients in focus groups and interviews (Rosmovits & Ziebland, 2004, p61).

An analysis of breast and prostate cancer online message boards revealed that the top three topics of discussion were: support (42.5%), medical/treatment information (33.6%), and emotional expression (19.3%) (Blanks & Adams-Blodnieks, 2003). Interestingly though, there were significant differences in the messaging behaviour between the two groups (Table 10).

Breast cancer messaging activities		Prostate cancer messaging activities	
Support	45.5%	Support	36.1%
Medical/treatment info	28.9%	Medical/treatment info	43.2%
Emotional expression	22.8%	Emotional expression	12.3%

Table 10: Comparison of activity on breast cancer and prostate cancer online message boards (figures taken from Blank & Adams-Blodnieks, 2003, p1253).

These figures may reflect the different needs of men and women; as we have seen women look mainly for support from their peers, whereas men tend to seek information.

In both the breast cancer and prostate cancer patients "Newly-Diagnosed" and "Open Discussion" forums, the majority of medical/treatment information messages concerned initial diagnosis and the various treatment options available, followed by treatment side-effects, rather than the effects or symptom of the cancer itself (Blank & Adams-Blodnieks, 2003, p1253). Perhaps reflecting their desire to access information in order to help them make informed decisions regarding treatment.

Emotional support is a need that has been described by many researchers, including Rai-Chaudhuri and Hogan (2004).

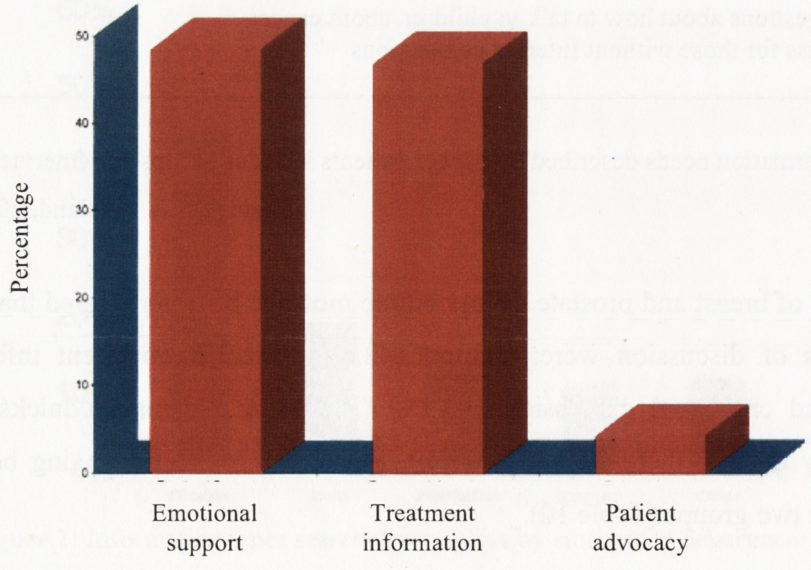

Figure 3: Topic breakdown of messages in a chronic myelogenous leukaemia discussion group (Rai-Chaudhuri & Hogan, 2004).

These authors found that, in an analysis of the content of messages exchanged in a chronic myelogenous leukaemia (CML) discussion group, the majority were focused on either support or treatment information (Figure 3).

Helft et al (2005) interviewed socio-economically disadvantaged cancer patients attending an urban hospital about their patterns of Internet use. Those patients that did use the Internet seemed to be most interested in gathering information about their treatment options, closely followed by general information about cancer (Table 11).

Information Topic	Frequency (% of patients)
Treatment options	81
General information about cancer	76
Nutrition and cancer	62
Alternative therapies	43
Ways to live with cancer	29
News articles about research and treatment	19

Table 11. Types of Information Sought (Helft et al, 2005, p4957)

Support for this interest in the mechanisms behind disease can be seen in patients with different conditions.

> I found an absolutely marvelous site I was really, really taken with it, it went into such clear explanations and with a breakdown of the different, oestrogen, progesterone, testosterone and what they actually do and how they link together.
>
> Participant (Sillence, Briggs, Harris & Fishwick, 2007b, p1858)

This may represent a desire to understand the science behind what is happening both in the disease and the potential treatments.

A survey of Asian patients joining a chronic myelogenous leukaemia (CML) support group revealed that 74% had joined the list to obtain information on treatment (Ramos, Rai-Chaudhuri, & Neill, 2004). This interest seemed to be recognised by those selecting the topics for the group as from 1999 there was a steady increase in

coverage of treatment information, and by 2002 it was by far the most popular topic (Figure 4).

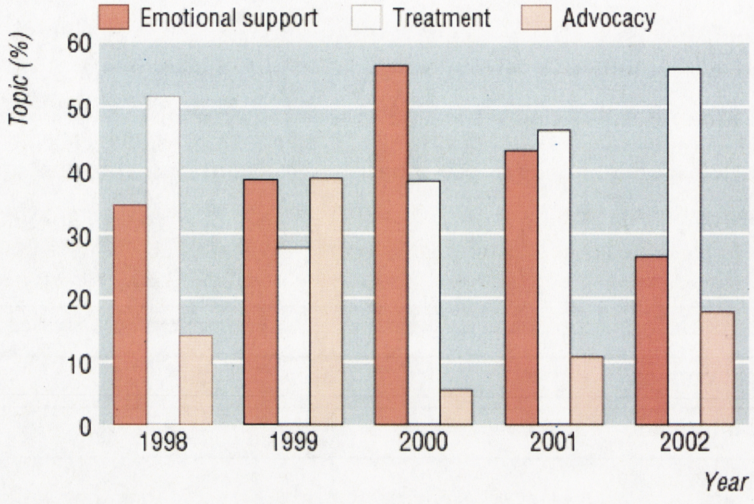

Figure 4: Random sampling of topics covered over five years by chronic myelogenous leukaemia international support group (Ramos et al, 2004, p1178).

There also seem to be differences in the information needs of cancer patients depending on their treatment stage. Newly diagnosed patients want information regarding the management of their disease, patients involved in clinical trials want more information about trials, and patients with metastatic disease are primarily interested in new clinical trials (Edgar et al, 2002, p443).

A qualitative study by Ziebland et al (2004) supported this idea. A 56-year-old breast cancer patient made the comment below, one year after diagnosis. It suggests that cancer patients go on an individual 'cancer journey', and that their needs for information fluctuate along the way.

> It's been helpful knowing where to look and being able to sort of follow the evidence and so on, but now I've reached the stage where I'm not looking anymore. It kind of comes and goes; to begin with I wanted a whole lot of information, but now I feel perhaps I don't want to know too much and I just want to try and keep going and not think too closely about what might happen.
>
> Patient (Ziebland et al, 2004, p565).

Another study also proposed that cancer patients' information needs are at their height during the period between diagnosis and treatment (Rozmovits & Ziebland 2004). Directly after diagnosis patients are too overwhelmed, so information can be lost on them. But a few days later, once the initial shock has subsided there often comes a great need for information.

Summary

From looking at previous studies, the two most popular search topics emerging appear to be emotional support, and medical or treatment information. It is probable that patients who do search for information online want both support and information, but these needs may come at different stages in their treatment.

Studies specifically of cancer patients all revealed a clear desire to research treatment options for a significant number of participants. This may indicate that cancer patients are aware that they do have options and it is in their best interests to make sure they make the right choice for them. This sheds some light on research question 2, and the kind of information needed by cancer patients. But what are the driving forces behind cancer patients seeking additional information?

7. Why do patients search for information online?

We know that many patients search for information regarding their condition on the Internet. But we must consider why they feel the need to do this. In theory, their health care provider should supply them with sufficient information, support and time; however in practice it seems that this is not always the case. Is the increasing use of the Internet by patients an attempt to supplement incomplete care? Or is this merely a symptom of a fundamental change in patients' attitudes to disease and its treatment?

One participant commented, "I would look online first of all to get a feel for the issue before going to see my GP" (Sillence et al, 2007b, p1859). Many patients seem to consult the Internet even before their healthcare provider. This may be to reassure themselves of what the symptoms could mean and in some way prepare them for the doctors' diagnosis. Others might use the Internet to prepare for the consultation with their doctor; learning about their condition beforehand may enable them to ask more appropriate and relevant questions.

A survey carried out in 2001 showed that more than 50% of Canadian cancer patients felt that their doctor did not supply them with sufficient information about their condition (Chen & Siu, 2001). An example of this type of information deficit was reported in a study of an online discussion group for CML patients. It highlighted some fundamental problems that may arise in the treatment of less common cancer types. Oncologists who were unaware of Imatinib Mesylate's status as the treatment of choice for CML, often continued to treat patients with older, less effective options. There were oncologists who were unaware of correct dosages of Imatinib. Also, some oncologists were unaware of the recommended disease monitoring tests and their frequencies. Poor treatment of side effects and the high cost of Imatinib were also commented upon (Rai-Chaudhuri & Hogan, 2004). These findings are particularly worrying as they suggest a prevalent level of incompetence in oncologists in dealing with a rarer yet life-threatening cancer, which may be significantly damaging many CML patients health care.

Patients have reported that although their doctors seem willing to answer any questions they might have, they do not tend to initiate discussion of available treatment options. This means that patients *must* be well informed to know what questions to ask (Rozmovits & Ziebland, 2004).

Gattellari, Butow and Tattersall (2001) investigated to what extent cancer patients' information needs are met by their physicians. In all information categories more patients reported receiving too little information than reported receiving too much. The most reported deficits were in information about the future, treatment options and their side effects, and treatment recommendations (Table 12).

Information mismatches			
Item	Too much info	The right amount	Too little info
Information needs:			
- Information about illness	21	15	29
- Feedback about what's happening to illness	27	21	31
- Information about likely future	24	24	38
- Information about treatment options and side effects	16	14	37
- A treatment recommendation	11	10	21
- What medical care will achieve	27	32	34
- Information about risks to family	28	25	36

Table 12: Information mismatches in patient expectation and physician provision of information (adapted from Gattellari et al, 2001, p1873)

This deficit in the information supplied by physicians was also highlighted by a patient interviewed by Ziebland (2004), "When asked what information about prostate cancer treatments he had at this stage he remembers being given 'nothing, zero, would you like a cup of tea sort of thing' at the hospital" (p1789). When neither his general practitioner (GP) nor the consultant urologist provided sufficient information about his available treatment options; he went on the Internet to research both his condition and his treatment options (Ziebland, 2004).

Another study investigated the satisfaction of cancer patients scheduled to receive radiotherapy with the information they received from their physician. One in five

patients were not satisfied (Jones, Pearson, McGregor, Harper Gilmour, Atkinson et al, 1999).

Patients often use the Internet to "check up" on their doctor's information. This may be due to receiving confusing or contradictory information, or simply understanding that doctors do not know everything (Shaw, Han, Hawkins, Stewart, McTavish et al, 2007) and do not necessarily have the time or skills to explain everything.

> I don't expect a surgeon to spend hours on end trying to describe what he was going to perform and what he was going to make your lifestyle after surgery. I think [the Internet] is something which one needs to have access [to] because they are not going to be able to commit themselves to that length of time...
>
> Participant (Ziebland et al, 2004, p 567).

Breast and prostate cancer patients surveyed about their experiences with health-care professionals reported that the information supplied had been "patchy, inconsistent, contradictory and haphazard". Major issues included: physician's bias towards particular treatment options, time constraints, and poor communication skills (Rozmovits & Ziebland, 2004).

Sometimes patients use the Internet to decipher medical jargon. Health care professionals often forget that relatively common terms such as "catheter" and "radical hysterectomy" are not necessarily obvious to the patient and may cause further confusion and distress (Ziebland et al, 2004). Patients are also realising that when they receive advice from their doctor it simply represents one opinion. The Internet provides the ideal place for patients to see their situation from different viewpoints and check out alternative opinions (Sillence et al, 2007c).

For many patients, the belief is that knowledge equals power, "Knowledge is power and I needed to know that what was happening with me was the right thing. It turned out it was, the surgeons, the oncologists, the radiologists have been absolutely perfect with me..." (patient from Ziebland's 2004 study, p1788).

Many cancer patients are happy with the advice they receive from their doctors, but still want to reassure themselves that they have all the available information (Eysenbach, 2003). The Internet provides a portal to all the information they need to acquire this knowledge. They use information found online to review, validate and supplement advice received from their doctors. These patients want "to become partners in their own health" (Ball & Lillis, 2001; Shaw et al, 2007). Patients desire for active participation in their health care drives them to research their condition and their treatment options (Akesson, Saveman, & Nilsson, 2007). This thirst for knowledge was apparent when 80% of radiotherapy patients surveyed expressed a desire for 'as much information as possible' (Jones et al, 1999).

A patient in Ziebland's 2004 study voiced this desire, "Get involved, be part of your own cure. It's really cathartic, it's, being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease" (p568).

> The ability to access a wide range of disparate information on the Internet, coupled with the opportunity to present themselves as technically proficient and discriminating users of such information, enabled respondents to display a modern form of competence and social fitness in the face of serious illness.
>
> (Ziebland et al, 2004, p566).

This process of gathering and analysing information on the Internet allows patients to act like "scientists", as was observed by Sillence et al (2007b). Patients have also identified this feature of the drive to understand their condition, "I think everyone can be their own researcher now really; you can be in charge of your own affairs and know what's what. Nobody can pull the wool over your eyes," (Ziebland et al, 2004, p567).

Summary

In attempting to come to some conclusions about what cancer patients need from an online resource (and answer research question 2), it is critical to consider *why* they feel driven to use the Internet to find information. What are their information needs?

The major reasons expressed by patients for using the Internet to research their disease are a lack of information available from their healthcare providers, and an increased desire in many to take control of their treatment. The Internet seems to have encouraged many patients, including cancer patients, to take more responsibility for their own healthcare.

But, having researched their conditions on the Internet, what kind of impact does the information have?

8. Impact of online health information

There is some conflict about this particular issue. For instance the 2003 Pew Report's figures claim that in 73% of health seekers, the Internet improves the health information and services they receive (Fox & Fallows, 2003). Whereas, the subsequent *Pew Online Health Search 2006* reported that only 53% of "health seekers" felt that their most recent health search had made an impact on either their own healthcare, or the care of someone else. The impact was significant for those who had "received a serious diagnosis or experienced a health crisis" (personally or someone close to them) during the previous year (Fox, 2006).

The effect of online health information also appears to vary depending on the education level of the health seeker. Surprisingly, people who possess a college degree are often more tentative and wary of online information than less educated users (see Table 13).

Feelings about last health search	All health seekers	Health seekers with high school diploma or less	Health seekers with college degree
Reassured that you could make appropriate health care decisions	74%	77%	72%
Confident to raise new questions or concerns about a health issue with their doctor	56%	54%	57%
Relieved or comforted by the information they found online	56%	64%	53%
Eager to share their new health or medical knowledge with others	51%	57%	45%
Overwhelmed by the amount of information they found online	25%	33%	20%
Frustrated by a lack of information or an inability to find what they were looking for online	22%	27%	18%
Confused by the information they found online	18%	24%	15%
Frightened by the serious or graphic nature of the information they found online	10%	13%	8%

Table 13: Survey of peoples' feelings about their last health search, n=1594 (Fox, 2006, p10).

One study observes that of patients using the Internet for health information, around one third reported that the information influenced a decision they made about their healthcare. However, the effect on healthcare utilisation (doctor visits, obtaining

prescriptions or pharmaceutical products) was minimal, with only about 5% being altered (Baker, Wagner, Singer & Bundorf, 2003).

In contrast, in a report published in 2000, 41% of people searching for health information online said that the information they found influenced their health-care decision making, and half of these reported an improvement in their personal health-care management (Fox & Rainie, 2000). These findings were corroborated in the Pew Online Health Search 2006 (Table 14). Of the 53% of users who report online information making an impact upon their healthcare, over half claim that it directly influenced a decision about how to treat a condition.

Internet users who say their last search had any kind of impact	
Affected a decision about how to treat a condition	**58%**
Changed their overall approach to maintaining their (or someone they take care of) health	**55%**
Led them to ask their doctor new questions or seek a second opinion	**54%**
Changed the way they think about diet, exercise, or stress management.	**44%**
Changed the way they cope with a chronic condition or manage pain.	**39%**
Affected a decision about whether to see a doctor.	**35%**

Table 14: Internet users who say their last search had any kind of impact (Fox, 2006)

A study of menopausal women who were provided with Internet access to research hormone replacement therapy (HRT) and its effects, found that nearly all participants said that the information they found online had affected their thinking or decision making to some degree. But few reported a fundamental change in behaviour. It seemed that rather than changing a treatment decision or attitude, online information served to reinforce a decision that had already been made (Sillence et al, 2007b).

These surveys do not come to any conclusive consensus regarding online health information and how it affects healthcare.

Similarly, studies specific to cancer patients show that online health information does not necessarily result in treatment changes. One study reported that only 3 of 17 patients felt that information they have found on the Internet was likely to change

their treatment (Edgar et al, 2002). In another study, 40% of cancer patients discussed information they had found online with their doctors, however only 5% said that the information affected their treatment decisions (Helft et al, 2005). However, there are studies that do suggest that information found online can influence patients' decisions. In a survey of the members of an Asian CML support group, a staggering 77% said that knowledge gained from online support groups had enabled them to make better decisions about treatment (Ramos et al, 2004, p1178).

In another example, the Internet has been known to positively influence cancer patient health care.

> A patient from a rural area in the US was being given sub-therapeutic doses of Imatinib by his oncologist, and not reaching remission. After being shown a published paper on proper disease management written by a top CML expert by the patient (who in turn received it from the support group) the doctor changed the dose to the therapeutic dose. The patient has since reached remission on the therapeutic dose.
>
> (Rai-Chaudhuri & Hogan 2004)

The US Food and Drug Administration (FDA) found that in a study of 500 doctors, the majority agreed that Internet advertising (pharmaceutical companies directly targeting consumers online) had expanded their patients' awareness of available treatments, and their involvement in their own health care. These treatment promotions can even initiate discussion between doctor and patient, resulting in required treatments being prescribed (not necessarily the one advertised) (Berg, 2005).

The value of online health information simply as a method of improving health care for cancer patients is debatable. Many papers suggest that its influence on patient decision-making is secondary to doctor opinion. However, a number of cases have been reported that show online information can help patients make the correct treatment choices for them, and as the options in cancer treatment expand so may the role of the treatment information web site in these choices.

Patient empowerment

A huge impact on cancer patients accessing information online is their feelings of empowerment and perceived control over their condition. There is also an attempt to make sense of their cancer experience (Ziebland, 2004). Edgar et al (2002) report that most subjects felt empowered by the information they found online, and felt a greater sense of personal control. The information seemed to help improve their focus and at the same time ease their fears on certain issues. One participant commented, "This meant so much to me. I needed information. I knew nothing about it before," and another said, "It gave me more control over my disease" (Edgar et al, 2002, p443).

Additionally, in a study of socioeconomically disadvantaged cancer patients, "sixty-two percent of users reported that Internet information had made them feel more hopeful about their disease" (Helft et al, 2005, p4957).

Participants in Sillence et al's (2007a) study said that after a period of using the Internet to research their medical conditions they had a "new found confidence with respect to doctors and medical information" (p39).

> It made me realise that I felt a lot better equipped to go to the doctor than I had done. Prior to that I had just taken her advice, adding a bit of common sense and not a lot else, but I think that research I did has really made me think about looking into things further, rather than just accepting people's advice without looking at it yourself.
>
> Participant (Sillence et al, 2007b, p1860)

However, in the same study 33% of patients reported feeling confusion after reading online cancer information and 24% felt increased anxiety. This could be due to them accessing poor quality information, misunderstanding/misinterpreting information, or feeling confused by their options and anxious about which to choose. This study focused on socioeconomically disadvantaged cancer patients, which may have a bearing on this finding as only 4% of the sample had a college degree. They also found that fewer years of formal education was significantly associated with reporting confusion resulting from access to online information (Helft et al, 2005).

The effects of empowering cancer patients can be easily seen. In 1999 the 1500 members of 'The Chronic Myelogenous Leukaemia International Support Group' petitioned a drug company manufacturing a new drug for their cancer (Imatinib) to increase production. This resulted in the opening of 19 extra clinical trial centres, and demonstrated the force of patient power (Ramos et al, 2004).

Doctor-patient relationships/satisfaction with care

Patients researching their condition and treatment options can significantly affect the doctor-patient dynamic. There are concerns that this relationship could be undermined, and consequently be detrimental to patients' treatment. Indeed one study reported that 17% of doctors who have experienced patients approaching them with information found online felt that their authority was being challenged (Murray, Lo, Pollack, Donelan, Catania et al, 2003).

However, this study also showed that only 4% of the physicians believed Internet treatment information had a negative impact on the health outcome. Two factors were found to be associated with this negative impact: the doctor perceiving the information to be inaccurate, or the doctor feeling that the patient was challenging them.

A good example of the potential impact of patients seeking treatment information was one of the interviewees from Ziebland's 2004 study. Graham, a newly diagnosed prostate cancer patient, dissatisfied with the information he received from his doctors, went online to research them himself. His doctors had suggested electron beam radiation (EBR). But Ziebland observed that, "Graham was unimpressed by the EBR equipment which he had reason to believe was rather outdated. He told the eminent radiologist as much and their relationship did not prosper" (Ziebland, 2004, p1790).

So Graham went on to seek private health care and used a relatively new therapy that he had read about online. In Ziebland's interview he commented, "It's bad, it is really bad out there, which means many people who go in and are confirmed with it will just be given a treatment and not explained what it's about" (Ziebland, 2004, p1790).

Graham's experience with National Health Service doctors and their resistance to his ideas and research led him to believe they felt threatened by his knowledge. His view of their attitude to him was, "Hey, you think you want to be a doctor, I'm not treating you" (Ziebland, 2004, p1790).

But obviously this is just one side of the story, and very subjective. In the paper, Graham does appear to be very single-minded, and it is possible his attitude antagonised the doctors. It is also possible that the new therapy Graham wanted was simply not available to the NHS physicians, whereas privately these obstacles do not exist.

Despite concerns over the potential impact on doctor-patient relationships, many studies have suggested that online health education, far from undermining the doctor-patient relationship, may help to strengthen it. A consequence of patient empowerment is that this new-found knowledge allows patients to better formulate questions for their doctors (Edgar et al, 2002). With patients and doctors being on a more equal footing, partnerships can form when doctors embrace patient education.

> "I think an educated patient is a compliant patient and a good patient," says Jonathan A Bernstein, MD, associate professor of medicine, University of Cincinnati. "Some [physicians] say, 'I'm the doctor. Do this, take this, and don't question me.' But I think that kind of attitude is changing among physicians, and it should be changing"
>
> (Berg, 2005, p29).

This suggestion is supported by a study of menopausal women searching for online advice regarding HRT. They found that although the resources the women found did influence their treatment decisions to some extent, the opinion of their doctor remained the most important factor in the decision-making process (Sillence et al, 2007b, p1861). However, patients gathering information online encourages them to take a more active role in the doctor-patient partnership, which may "foster autonomy, and lead to more satisfaction with the medical system" (Akesson et al, 2007, p9).

A potential pitfall has arisen, as it has been suggested that many patients are reticent in discussing information they have found online with their doctors for fear of jeopardising such an important relationship (Ziebland et al, 2004, p568). It is vital that patients feel confident and comfortable discussing anything with their doctors, especially information which may affect crucial treatment choices.

Shaw et al (2007) investigated the effects of the availability and use of interactive cancer communication systems (i.e. essentially the Internet) on cancer patients' perception of their relationship with their doctor (Figure 5).

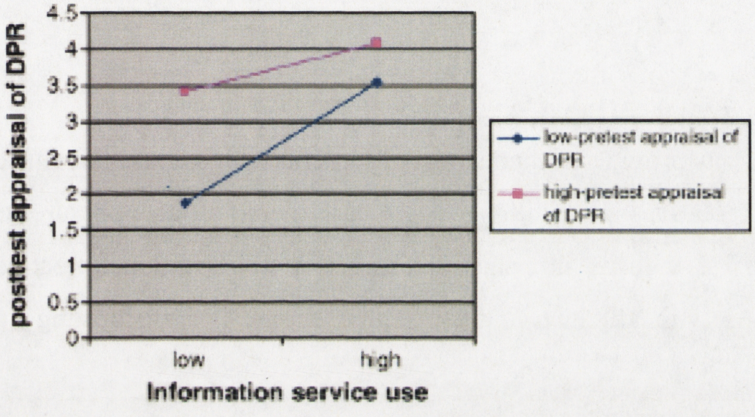

Figure 5: Interaction between information service use and pre-test appraisal of doctor-patient relationship (DPR) predicting post-test appraisal of DPR (Shaw et al, 2007, p280).

Interestingly those who had a more negative view of their doctor-patient relationship tended to use the system more. This may indicate them having less trust and confidence in their doctor. But, there was a statistically significant improvement in the appraisal of the doctor-patient relationship by patients that used the system. Suggesting that a patient having possession and access to knowledge generally improves their confidence in their relations with their doctor. However, an investigation of the effects of providing Internet access to medical information to patients undergoing *in vitro* fertilisation suggested that despite patients using the resource and being happy with it, there was no perceived increase in satisfaction in their medical care (Tuil, Verhaak, Braat, de Vries Robbe & Kremer, 2007).

There are also several studies that illustrate the fragility of the doctor-patient relationship. One study reported the case of a 27-year-old woman diagnosed with

cervical cancer who brought up the issue of cryo-ovarian preservation with her doctors after her mother found information about it online, she commented "...actually they were a bit dismissive about it to be honest, and it certainly wasn't something they would have offered me if I had not brought it up" (Ziebland et al, 2004, p567).

The woman was subsequently referred to another hospital where she was able to have the procedure. Although her experience of approaching the doctors about an additional treatment to preserve her fertility initially met with some resistance, the ultimate result was that her research led to improved healthcare.

The transition from patient to consumer

The Internet has provided patients (or consumers) with *choice*. Patients can now have access to alternatives to traditional healthcare including acupuncture and nutritional supplements, as well as information about various traditional treatments for their condition. As with all other industries this choice is transforming "patients" into "consumers".

> With its capacity for inexpensively retrieving information when, where, and how it is needed, the Internet is already transforming the physician/patient encounters. In fact, the word 'patient' is being slowly replaced, at least implicitly, by 'consumer'. As increasing numbers of healthcare consumers demand a more active role in their own care, the two sides of the power scale are edging towards balance.
>
> (Ball & Lillis, 2001, p2)

Summary

Access to medical information online may be of most use to patients for general peace of mind and empowerment, rather than for making alternative treatment decisions. Certainly, if people feel more positive and in control of their condition due to this information, this is sufficient reason for such resources. A patient in one study highlighted this, "everyone is different, for me getting the information was what kept

me going on a daily basis before I went in for my operation, you know, just having things to read about," (Rozmovits and Ziebland, 2004, p59).

In terms of improved health care, the impact of online information can be of vast benefit, particularly if the patient is receiving sub-optimal care, for instance the CML patient and Imatinib mesylate example. However, for the most part patients seem to be content with their care and simply use information to support their decisions, and reassure themselves that they are in good hands.

Other impacts that online health information may have include the doctor-patient relationship, which despite fears from some physicians appears to be strengthened and balanced by patient education more often than it is damaged.

Finally, the Internet has catalysed the evolution of patients into consumers. Gradually patients are realising there are options out there and it is their responsibility to find the best option for them. However, as a provider of cancer treatment information, the potential impact of the information on cancer patients must be considered when deciding what the patient *needs* (research question 2).

To address research question 3 (how can cancer treatments be presented in a web site?), first the key issues that accompany providing health information online will be considered.

9. Searching for cancer information online

Health related websites are amongst the most widely-used on the Internet (Wilson & Risk, 2002). The quality of health resources available online is an area of concern, especially, the responsibility this places upon patients to find and evaluate such resources (Ziebland, 2004).

A patient in this study commented,

> ...there is a whole mass of information in the Internet. If you just go in with the keyword prostate you'll be reading til you die in any case. It's tremendous...and there are lists where everyday everything is pumped down to you...I normally hit the delete key...but the information is there and there are at least five very, very good technical sites.
>
> Patient (Ziebland, 2004, p1791)

Most patients who use the Internet to obtain information about their condition do raise concerns about the quality of the information available, and the difficulties this presents to other patients in evaluating it. Interestingly though they exclude themselves from this, suggesting a certain amount of confidence in their own discriminatory skills (Ziebland et al, 2004).

There are several organisations that have produced guidelines in an attempt to maintain quality in health related websites, including the eHealth Code of Ethics of the Internet Health Coalition, whose vision statement reads:

> The goal of the ***eHealth Code of Ethics*** is to ensure that people worldwide can confidently and with full understanding of known risks realise the potential of the Internet in managing their own health and the health of those in their care.
>
> (Rippen & Risk, 2000, p1)

The extent to which such guidelines are being implemented is unclear. Websites that do adhere to codes of conduct can display the seal of that organisation (once the content of their website has been assessed). Endorsed websites can be checked by the

ethical body, and users can also alert them to any violations (Wilson & Risk, 2002). There are also "user guidance systems" available online to help searchers to evaluate websites. For instance DISCERN (www.discern.org.uk) is a brief questionnaire that aims to prompt users to ask questions of health websites, such as "are the aims clear?" Other services are also available to assist health searchers including filtering tools. For instance, intute (www.intute.ac.uk/healthandlifesciences/) is a gateway to evaluated, quality web health resources.

However, whether users are actually aware of these services is unclear, and whether those who are have the time or inclination to use them is also contentious. As Wilson and Risk (2002) point out, "quality remains an inherently subjective assessment" – who decides what is quality information for a particular audience?

In one investigation, participants were presented with a random selection of health/medical related questions and asked to use the Internet to find the correct answers. The vast majority of participants used general search engines such as Google and Yahoo! to find relevant websites. Most of their searches consisted of only one search term; for instance the disease name, when combining search terms would be much more effective. Participants tended to choose one of the first search results displayed and rarely looked at the second page of results, instead re-phrasing their original search (Eysenbach & Kohler, 2002). However, despite these somewhat ineffective search strategies the participants were very effective in retrieving the desired information, with only seven of the 136 questions posed being unanswered. There seemed to be no disparity in search time between inexperienced and experienced Internet users, with both averaging around five minutes per question. Interestingly, none of the participants sought to find out who stood behind the website or where they had got their information. But this may be because they were not searching for information affecting them or their healthcare and were just answering isolated questions.

Eysenbach and Kohler's (2002) qualitative study of consumers' appraisals of the information available on the Internet highlighted certain areas of importance (2002). Consumers tend to look for websites produced by official authorities (charities, government), with a professional interface, well-written content using simple

language, access to source material and links to other respectable websites. Websites with lots of advertising were usually avoided, "I have been on a [AIDS] site that was not too bad actually, but there have been some strange banners on top [advertising banners for pornographic websites]. This, of course, badly affected the credibility of that site" (participant, Eysenbach & Kohler, 2002, p574).

> ...it's got to be somebody reputable, you know, you can't get scaremongers on there or wishful thinkers...I'd want to know who endorsed your information, supported your information, were they medically qualified, who were behind you...you've got to be able to prove to people on the Internet that you're a reputable body and you're serious about it.
>
> Patient (Rozmovits & Ziebland, 2004, p60)

Another participant observed, "I liked all the information and everything but when I got to the end I realized it was all sponsored by drug companies...it just disappointed me cos I thought it was really great until I realized that" (Sillence et al, 2007b, p1858).

The study by Sillence et al 2007(a) study corroborated these findings; their participants also used popular search engines in their quest for information, and they noted a marked lack of trust by participants for sites with obvious commercial activity. Silence et al (2007a) also suggested that when people search for health information online, the basis on which they reject websites is usually based upon the interface design. In fact, 83% of the weight fell on design when users initially assessed websites, and only 17% on the content (Table 15).

Type of factor	Specific aspects of the site	Weighting
Design	Adverts Small text Amateur design Overly commercial Spelling mistakes Colour Busy, complex layout No navigational aids Poor graphics Too much text Broken links Boring or bland design	**83%**
Content	Too much jargon Lack of useful content	**17%**

Table 15: Factors relating to the rejection and mistrust of websites (from Sillence et al, 2007a, p36).

Once a site had been provisionally accepted by the user, (usually based on its visual appeal), a different set of criteria was used by most participants to evaluate its trustworthiness. These tended to be more information focused; and participants usually referred to the content rather than design when talking about websites they trusted most. The most important factor seemed to be the site's content being in-depth and comprehensive, other factors included; the organisation responsible for the site, a clear aim/motivation behind the site, and specific advice from medical experts. The participants also compared information found on different sites, and became suspicious if different resources did not agree. The processes involved in building user trust are depicted by the staged model of trust (Figure 6).

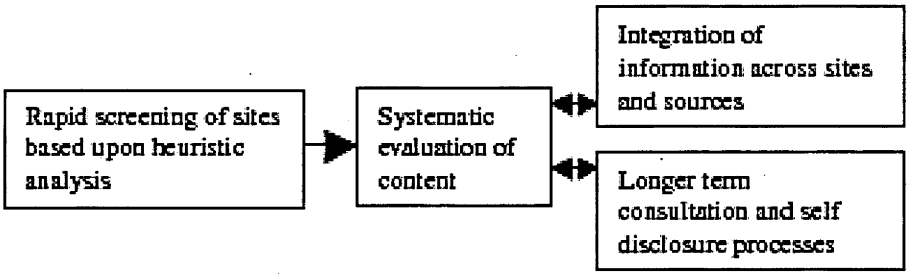

Figure 6: The staged model of trust (Sillence et al, 2007a, p34).

Rozmovits and Ziebland (2004) also reported that all the cancer patients in their study who had used the Internet to access health information were fully aware of the potential problems with it as an information resource.

Those patients who are utilising the Internet appear to be very conscientious in their evaluation; cross-checking information from similar sites, discussing what they have found with family, friends and their doctor, and reflecting carefully on what they have found (Sillence et al, 2007a).

2000	2005
1. The site contained contributions from like-minded people	1. The site was easy to use
2. The advice came from a knowledgeable source	2. The advice came from a knowledgeable source
3. I felt involved in the way the site tried to find appropriate advice	3. The advice appeared to be prepared by an expert
4. The site was easy to use	4. The advice appeared to be impartial and independent
5. The advice appeared to be impartial and independent	5. The reasoning behind the advice was explained to me

Table 16: The top five most important trust markers for health websites in 2000 and 2005 (taken from Sillence et al, 2007c, p402)

Table 16 charts how users of health websites criteria have changed between 2000 and 2005. The most notable development is that the major focus seems to have become more on the quality and validity of the content. The importance of the sites' usability

has also increased since 2000, suggesting that patients are becoming more impatient, and perhaps realising that if one site is difficult to use they can easily find another.

	2000	2005
Number of individual sites reported	155	250
Top three most reported sites (no times reported)	WebMD (159) DrKoop (41) Mayoclinic (24)	WebMD (216) NHSdirect (24) Mayoclinic (18)
Percentage of general portal sites	8%	5%
Percentage of domain specific sites	22%	27%
Percentage of specific topic sites	70%	69%

Table 17: Breakdown of health sites in 2000 and 2005 (adapted from Sillence et al 2007c, p402)

Table 17 shows that specific topic sites (sites dedicated to a specific disease/condition) are by far and away the most popular in health searches, followed by domain specific sites such as 'NHSdirect' that cover a range of health issues, and lastly general portals which cover a huge array of topics one being health.

In a meta-analysis of health website content evaluations, 70% of these studies suggested that quality is a problem regarding Internet health resources (Eysenbach & Kohler, 2002). However, studies into the value of web resources on cancer have generally been positive. A study into the information available online about breast cancer (Santoro, 2003) found that the quality of information available at the time was good. But the continuing development of preventative, diagnostic, treatment, and prognosis information available is required to improve patient education.

Table 18 shows the results of an analysis of 184 sites containing information about breast cancer including the quality of the information provided (Meric, Bernstam, Mirza, Hunt, Ames et al, 2002).

Characteristic	Sites
Affiliation:	
Commercial	46%
Non-profit organisation	35%
University or medical centre	12%
Government	8%
Specialisation:	
Breast cancer exclusively	51%
Breast cancer pages of health site	49%
Content type:	
Medical facts	82%
Opportunities for psychosocial adjustment	35%
Human interest stories	26%
Ongoing available trials	19%
Message board service	13%
Results of clinical trials	8%
Chat site	8%
Site for medical questions	6%

Table 18. Characteristics of breast cancer websites (Meric et al, 2002, p578).

Commercial and non-profit organisations make up the majority of sites containing information about breast cancer when searched for using Google. The content of these sites almost always includes medical facts. Fifteen percent of the sites analysed displayed a 'Health on the Net' (HON) seal, but not one of these sites actually complied with all eight of HON's criteria, or the four JAMA (Journal of the American Medical Association) benchmarks. Only seven percent of the 184 websites evaluated by a breast oncologist were deemed to contain inaccurate medical statements.

Figure 7 shows that those websites that did meet with three or more of the JAMA quality criteria were much less likely to contain inaccurate medical statements than sites that met with two or less.

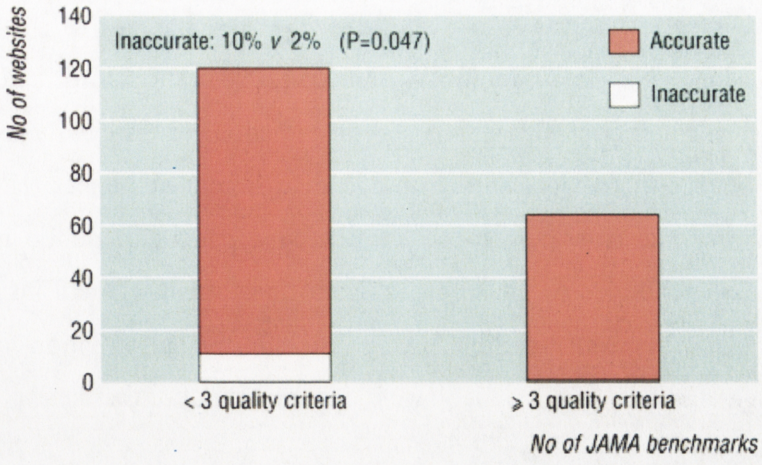

Figure 7: Number of accurate and inaccurate websites, based on number of JAMA benchmarks met. A website was considered inaccurate if it contained one or more inaccurate statements (Meric et al, 2002, p579).

However, as the graph shows even those websites that did not meet with JAMA's benchmarks contained very little inaccurate information.

Summary

Issues highlighted by people searching for health information online include issues of quality and accuracy; patients need to feel they can trust the website to give them the correct information. This trust is initially associated with more superficial aspects of the site such as the interface design; users tend to trust professional and easy to use web sites. Once the user has selected an aesthetically trustworthy site they assess the content, focusing their attention on who is responsible for the site (is it recognisable and trustworthy organisation?), what are the aims of the site, and is the information comprehensive and understandable? Users are wary of sites containing commercial activity, and often even compare information with other sources to gauge its accuracy.

This reveals some important issues to be aware of when considering research question 3: how can cancer treatment information be presented in a website? To more fully address this question, a review of currently available resources and how they present treatment information (specifically how they work) must be undertaken.

10. Current online sites and treatment information

In a paper by Junghans, Sevin, Ionin and Seifried (2004) cancer information resources available on the Internet are identified and described. There is clearly a great wealth of information out there targeted at a range of different audiences. However, how treatments work does not seem to be considered a patient or public informational need. The sites mentioned in the study as useful for patients (OncoLink, Cancer.gov and CancerIndex) are all credible resources offering information and support. However, a general lack of pharmacology is apparent in all of these.

Studies of the cancer information available for patients on the Internet are concerned with whether the resources are accurate, up-to-date and reliable. These are all very important points, however they do not really address the issue of whether there are websites containing explanations of the underlying pharmacology – the issue that affects the proposed website. Without any previous studies of the provision of information about how cancer treatments work on the Internet, a brief review of the current cancer information resources available online was carried out.

a) Journals

There is a huge array of information available on the Internet through journal websites. For instance, the *Journal of Clinical Oncology*, *Cancer*, the *European Journal of Cancer*, the *Journal of the National Cancer Institute*, and *The Oncologist* are examples of publications that deal with cancer specifically. There are also journals that deal solely with specific cancers (such as *The Breast*), and of course general medical journals including the *British Medical Journal.*

Articles and reviews are available to the public usually around 6 months after they are published so they are an ideal resource for getting up to date and accurate information on cancer treatment developments. However, unless the user is accustomed to reading medical journal articles and familiar with scientific jargon, these articles are completely unintelligible. Even for scientists, it is often difficult to extract meaning.

b) Charity or government groups

The Internet is a powerful and important medium for charity groups. In a 2001 study it was shown that all neurological charities surveyed either had a website or were

planning to establish one (Fox, 2001, p156). This obvious endorsement of the value of the Internet in reaching their target audience is almost certainly shared by cancer charities; indeed there are a huge number of cancer charities with websites several of which are discussed below. Charitable organisations are important providers of information to the public and more specifically patients as they are seen as trustworthy and responsible guardians of the population. To fairly compare sites on their provision of specific pharmacological information, the anticancer drug imatinib mesylate (or trade name Glivec/Gleevec) was searched for. The depth, quality and format of the information provided was then reviewed.

Cancer Research UK (cancerresearch.org.uk)

Cancer Research UK is the UK's leading charity dedicated to cancer research. The website also offers patient information on cancer, with a section dedicated to cancer drugs. Imatinib (Glivec) has a page that is mostly concerned with detailing the potential side effects of the treatment. There are around five sentences explaining what Imatinib is and how it works against cancer. There are no diagrams or pictures to explain the concepts.

Cancerlink (cancerlink.org)

Cancerlink is the support website for cancer patients run by the Macmillan Cancer Support charity. There is no information about specific cancer drugs at all, and limited information about general treatments such as chemotherapy. Site searches for Imatinib, Glivec or Gleevec yielded no results.

Cancerbackup (cancerbackup.org.uk)

This website has a much more information-based focus. It is partnered with Cancer Research UK, and their joint aim is to "inform and empower patients". This is the first support website assessed that had any pharmacological information about cancer drugs at all. The information itself is very clear and written well but is not comprehensive, the section on Imatinib is only a couple of paragraphs long and fairly technical. There are no diagrams to support the text and explain the concepts described.

National Cancer Institute (cancer.gov)

This is the website of the US National Cancer Institute. It has information about all aspects of cancer; the disease, the treatment options, clinical trial information and so on. This information is presented in two different forms, one specifically for patients and one for health professionals. Selecting the patient option presents the user with no information on the method of action. The health professional information is highly technical, and therefore unsuitable for the lay audience.

Dipex (dipex.org)

The tag line of the Dipex site is "personal experiences of health and illness". This clearly points to what the aims of the site are; it seeks to offer support and advice to patients through connecting them with other patients. The site houses forums for discussion, interviews (text, audio and video), and lots of links to other useful sites. However, apart from information given via other patients and a small and fairly lightweight Q&A section, the Dipex site only offers treatment and drug information through links with other cancer sites. There were no search results for Imatinib, Glivec or Gleevec.

Expert Patients (expertpatients.nhs.uk)

The NHS in the UK has launched a scheme called 'expert patients' in an effort to educate and empower patients with long-term illnesses. The programme is a "self-management course giving people the confidence, skills and knowledge to manage their condition better and be more in control of their lives". However, it is not an information resource, but rather provides courses and support for people dealing with long-term conditions.

Cancer Council Australia (cancer.org.au)

The leading independent funding organisation of cancer research in Australia, the Cancer Council also offers support and information to cancer patients. Searching for information about the anticancer drug Imatinib on the website revealed no results though. Treatment information available on this website was confined to general treatment types such as chemotherapy and radiotherapy, and did not address specific drugs.

c) Commercial

There are now a number of commercial medical websites popping up online, probably in response to the metamorphosis of patients into consumers.

Cancer Consultants (cancerconsultants.com)

The company describes itself as "the preferred online destination for reliable information covering the prevention, screening, and management of cancer in English and Spanish for leading providers of cancer care in the United States". The site has a 'drug dictionary' facility that includes a page for Imatinib, however the mechanism of action information is very brief and technical, using language such as 'tyrosine kinase inhibitor', 'c-Kit positive' and 'growth signaling processes' without adequate explanation of what these terms mean. There is no attempt to use diagrams in explaining any of the concepts involved.

webMD (webMD.com)

This website is a general health portal covering pretty much everything in good detail. In terms of drugs it offers: uses, side-effects, precautions, interactions and overdose information. There is a cursory, two sentence explanation of Imatinib action. But it does have good "latest headlines and features" section containing recent developments, and a section called 'How well it works' which provides a clear summary of clinical trial results.

Virtual Medical Centre (virtualmedicalcentre.com)

The Virtual Medical Centre has a specialised cancer section (Virtual Cancer Centre) with their aim being to 'help cancer patients, physicians and cancer specialists to be better informed about health and cancer related topics'. The search for information about the action of Imatinib brought up a page that included a paragraph explaining how the drug works againt chronic myelogenous leukemia and gastrointestinal tumours. The majority of the page was taken up with dose advice and side effects of the drug. No visual explanation of mechanism was provided.

d) Google

Simply typing the query 'How does Imatinib work?' into Google (a tactic used by

many Internet users) was also used to find applicable resources. The first ten results were:

1. GIST (gastrointestinal stromal tumour) support international website - gistsupport.org. Consisting of a technical explanation around one paragraph long.
2. FDA site (fda.gov). A Gleevec questions and answers page, which provided a couple of sentences explaining how the drug acts.
3. ABC Radio National (abc.net.au). A transcript from an interview from the radio show 'The Health Report' about Imatinib as a treatment for GISTs. The interview mainly focused on difficulties in being prescribed the drug and not on how it works.
4. C-health (chealth.canoe.ca). A commercial website that provided a single sentence description: "Imatinib works by affecting enzymes that play a role in certain cancer cells".

The next 6 results all came from journal articles and were therefore unsuitable for lay readers.

Summary

The overall conclusion regarding the provision of cancer treatment action information for patients on the Internet is that it is not really addressed. This may mean that it is not regarded as something that is required or desired by cancer patients, it may simply be because of the difficulties involved in explaining drug interactions to the lay person.

One thing that was particularly interesting about all the resources found is the complete lack of diagrams. All information is conveyed in blocks of text, which seems a very unhelpful way of explaining both disease progression and drug interactions, which are quite conceptual. This is an aspect that would be addressed in the proposed site.

Most websites prioritise "support" (both emotional and practical – addressing issues such as depression and financial concerns) over medical information. This obviously reflects the belief that this is what patients go online for. Interestingly, a study comparing the Internet users of Cancerbackup's website to their helpline callers (Hardyman, Hardy, Brodiaea & Stephens, 2005), found that Internet users focus their searches on facts, in contrast to people who call helplines, who are mainly looking for emotional support. In fact, 23% of callers had unsuccessfully looked for cancer information on the Internet before trying the helpline, and 71% of callers wanted treatment information specifically.

The majority of the websites reviewed were UK or US sites. It was very difficult to find Australian online resources at all. The only suitable Australian site was provided by the Cancer Council, and did not provide any information whatsoever about the anti-cancer drug Imatinib. This may show a fundamental deficit in the provision of treatment information available to Australian patients in comparison to those in the UK or US.

Roberts and Copeland (2001) commented that, "providers are failing to meet the challenges presented by the range of potential enquirers of their information" (p186).

This review of current websites shows a distinct lack of detailed treatment information and therefore could represent an unfulfilled patient need. The unimaginative presentation of what little treatment information there is may also suggest that a more graphical and interactive approach is required in explaining cancer treatments.

11) Online information about complementary and alternative treatments

The Internet provides the ideal environment for people wishing to take advantage of vulnerable patients seeking cures for their illnesses. This study is concerned with offering information about approved drugs and treatment types, but the issue of alternative therapies must be addressed.

Alternative therapies by definition are promoted for use in place of conventional treatment; this can cause problems because they not only delay medical treatment but such alternatives are often biologically active, harmful and expensive (Cassileth & Deng, 2004). Complementary therapy (which is often grouped with alternative medicine) is used in conjunction with conventional therapy as a supportive measure. Some complementary therapies have been proven safe and effective, and are now becoming integrated into standard cancer therapy (Cassileth & Deng, 2004).

Cassileth and Deng (2004) estimate that between 10% and 60% of cancer patients have used complementary and/or alternative therapies. The Internet has no doubt contributed to this boom, and CAM (complementary and alternative medicine) products can easily be purchased online. In a 2004 study of online CAM resources, Schmidt and Ernst reported that the majority of websites provided valuable and reliable information. For instance, the use of acupuncture and acupressure has been shown to prevent chemotherapy-related nausea, and massage decreases stress, anxiety, depression and pain in some cancer patients. However, a number of websites contained misleading and potentially dangerous information about CAMs. In fact of the top five 'cancer cures' they found on CAM sites, not one is supported by any scientific evidence. The relevance of their findings to the resources available currently is difficult to estimate, and there have been no further reviews of CAMs websites for cancer patients since.

Simply entering the query 'alternative cancer cure' into Google brings up a raft of sites promising miracle cures, including CancerTruth.net a site that claims that,

> ...case after case of natural cancer treatments (i.e. alternative cancer treatments), and even some orthodox cancer treatments, that were shut

down by the authorities (usually the AMA, FDA or FTC) because they were too effective at curing cancer!

Sites such as quackwatch.org try to help people 'spot quackery' and advise caution when it comes to alternative products. Clearly there is a significant presence of CAM cancer treatment information available online of varying quality and safety. Regulating this content to protect users is a huge challenge requiring a coordinated approach by all parties involved in communication with cancer patients. As a website explaining accepted treatments and therapies, links to reputable CAM sites with safe and reliable information for patients may help protect users.

Overall conclusions

In addressing the three research questions: research question 1: what evidence exists to support a web-based information resource? A review of current literature clearly shows a need for cancer patient education, that the Internet is an appropriate medium, and that cancer patients turn to online resources for health information.

In response to research question 2: what kind of information do cancer patients *need* about treatments? Although it is very difficult to definitively identify and isolate a "need" for cancer drug interaction explanation to the public, it is clear, however, from both the literature and the currently available online sites that there is a gap in the current information, and a niche to be filled.

Finally, research question 3 asked: how can cancer treatment information be presented in a website? The major factor in presenting medical information online is user trust. Many aspects of the site contribute to gaining or losing this trust and must be considered in design and information selection.

The aims of the web site

The central aim of the proposed website is to provide cancer patients with a comprehensive resource explaining the mechanisms by which cancer treatments work.

How can a treatment information website for cancer be designed?

There are a number of things to consider when designing a website. The method shown below was used to plan the overall structure and design of the website.

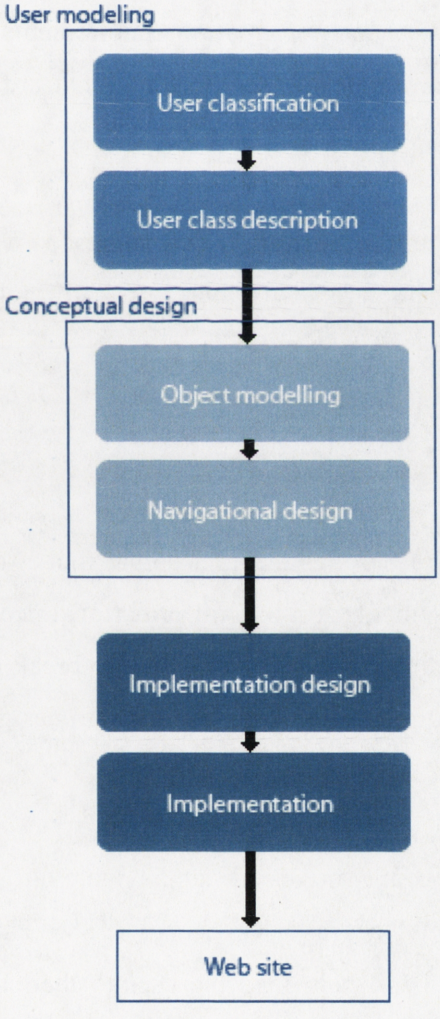

Figure 8: An overview of a user-centered method for the design of webites

(adapted from De Troyer & Leune, 1998; p88)

1. User modelling

When someone arrives at a web page they are usually looking for an answer to a particular question. An effective website should anticipate those questions and answer them. Therefore, the first step in designing a website is to think about the target audience and what their questions might be (De Troyer & Leune, 1998).

1.1 User classification

Who are the potential users of the website?

This step involves grouping potential users into classes depending on their information needs (De Troyer & Leune, 1998).

1.2 User class description

What are the characteristics and information requirements of the different users? What is their existing knowledge of the subject? What are their literacy skills and computer experience?

User classes are analysed in more detail to determine: (a) what information they are seeking, and (b) their characteristics, which will inform how this information is presented (De Troyer & Leune, 1998).

2. Conceptual design

2.1 Object modelling

The purpose of this phase is to create a conceptual model of the website structure, based upon the user requirements and their informational needs (De Troyer & Leune, 1998). This involves deciding on the way in which to break up the information to be presented. This process requires careful consideration to design a logical structure.

2.2 Navigational Design

This phase models the ways in which users can navigate through the website to arrive at the desired information (De Troyer & Leune, 1998). This involves constructing information pathways that will help lead the user to their desired information in a logical and fluent manner.

3. Implementation design

This step involves developing an appropriate 'look and feel' for the website (De Troyer & Leune, 1998).

The ultimate goal is to produce a website that is easy for users to navigate, and attractive and useful to all users regardless of age, education, or computer experience (Jones et al, 2001).

Design factors

The interface should be as visually appealing as possible. This includes a clear layout with a balance of text and graphics and good use of colour. Text should be presented in a large font to improve readability and preferably be broken up wherever possible with bullet points and sub-headings. It is advisable to leave some 'white space' (empty space), as this makes text easier to read. Important information should be fitted into one screen wherever possible, as many users will not bother to scroll. Finally, consistency throughout the website should be maintained. This lends a fluency and familiarity to the site (Gilmour, 2007; Sillence et al, 2006; Sillence et al, 2007a; NHS toolkit for producing patient information, 2003).

Presentation of information

Information should be presented in a style suitable for the web. In terms of text, readability is vital; language should be pitched at the reading level of a typical 12-14 year old, sentences should be kept short (10-15 words), and words themselves preferably under three syllables. Technical language should be avoided at all costs, but if it is used, clear definitions and a glossary must be included (Gilmour, *article in press*).

The overall tone of the information should be 'patient-friendly', making use of personal pronouns such as 'we' and 'you'. Use of present and active tenses also helps to create a personal and friendly feel. Alarming language should be avoided (NHS toolkit for producing patient information, 2003).

Wherever appropriate images, graphics and animations should be used. Many studies have highlighted the importance to users of visual explanations. Participants in a study by Jones et al (2001) identified "wonderful graphics" and "informative animations" as two of the most valuable features of their computer-based education program. Animations can be used as illuminating presentations of central principles, and graphics help make abstract concepts more tangible (Jones et al, 2001; Sillence et al, 2007b).

Navigation issues

The website must be easy and intuitive to navigate through. The goal is to lead the user to their desired information in a logical and natural way.

The website should accommodate varying user search abilities and preferences by providing a number of different navigational facilities; a site map, a search function on the homepage, menus and 'breadcrumbs' to show the user where they have already been. Consistency and familiarity also play a role in navigation; for instance all the hyperlinks within a site should behave in the same way, and preferably in a way that is familiar to users from other websites. Additional factors to take into account include a spelling approximation function in the search application, external links that should open in new windows so that users do not accidentally leave the site, and 'back-to-top' anchors. The number of 'clicks' it takes to reach the desired page should also be minimised (Gilmour, 2007; Sillence et al, 2007a; Sillence et al, 2007b; Cline & Haynes, 2001).

User trust

Certain features of health information websites have been identified as important in establishing user trust, including: clearly identified authorship, attribution (references and sources), seals of approval from other organisations, opportunities for users to leave feedback or ask questions, disclosure of mission statement or purpose of the site, disclosure of any potential conflicts of interest, and links to external sites (Cline & Haynes, 2001).

Users seem to be very concerned about the motivations behind sites, so these should be made obvious. Users are also distrustful of sites that appear to be commercial in any way (Sillence et al, 2007a).

4. Implementation

The last phase concerns the process of constructing the final website as planned (De Troyer & Leune, 1998).

The development of this website

1. User modelling

1.1 User classification

The majority of people visiting this type of information resource would be those affected by cancer, and/or interested in treatment options. These are: cancer patients, and the friends and family of cancer patients.

This represents a diverse group of people with varying learning styles, levels of knowledge and language skills to consider when presenting information (Jones et al, 2001).

1.2 *User class description*

The age range of the potential users for a website based around cancer treatment is very wide. Although the younger demographic is more likely to look for information on the Internet, cancer is a disease that typically affects older age groups, so the website attempts to cater for people of all ages.

In particular, care was taken to make the website accessible and usable for older adults. Older adults represent a growing population of online consumers, with around 22% of over-65's having already used online services in the U.S. (Fox, 2004).

The selection of information of appropriate complexity for the audience requires careful consideration (Jones et al, 2001). The levels of education, literacy, and the level of scientific knowledge of potential users must also be considered. Some scientific literacy can be expected from visitors to the website. As was shown by Fox and Fallows (2003), people who look for health information online tend to be better educated. The fact that they are interested in this type of information suggests a certain confidence in their ability to understand scientific concepts and terminology. However, the information level must not exclude any potential users. Cancer is indiscriminate and therefore efforts should be made to make the information intelligible to as wide an audience as possible. The information content is therefore pitched at around the reading level of a year 10 (14 year old) high school student. This means that some basic understanding of simple life processes was assumed.

In considering computer literacy, health information websites should cater to all levels of competence. The website was therefore designed to be as intuitive and straightforward as possible with respect to navigation and use.

Finally, the information needs of the potential users of the website were analysed with a user-centred approach.

> Groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews, and involve multidisciplinary teams (including patients) in developing and testing the material.
>
> (Coulter A, 1998, p225)

Ideally, this would involve both qualitative and quantitative approaches to gathering information concerning the "needs" of the target audience. This would include: looking at current resources and literature, and also using surveys, interviews and focus groups of the audience (cancer patients) to establish what they want (Kinzie, Cohn, Julian & Knaus, 2002).

However, due to time constraints only a review of past literature and existing web resources was possible. The lack of patient input is a limitation of the method.

The outcome of examining previous literature and existing information available to cancer patients online (see Chapter Two) suggests that mechanistic cancer treatment information is lacking online, and that it may represent an information need for cancer patients. Other major "needs" that emerged from the literature and resource review included: the importance to patients of a facility for asking questions (Jones et al, 2001; Sillence et al, 2007b; Sillence et al, 2007c); the desire for visual explanations of complex concepts (Jones et al, 2001); and the need for a glossary of medical terms (Gilmour, 2007).

Previous literature does suggest a general desire amongst cancer patients for more biomedical information, particularly concerning treatment options (see Chapter 2, section 7). However, this need is not well defined and further investigation is required

into exactly what aspects of biomedical treatment information are wanted by cancer patients. Therefore, when designing this website, a comprehensive overview of cancer treatment information including, biochemical mechanisms, clinical efficacy, potential side effects, and news/developments, was attempted.

Although patients also express a desire for information about other aspects of cancer such as emotional support and financial advice (Rozmovits & Ziebland, 2004), the review of currently available web resources revealed that these needs are already addressed on the Internet. Links to websites catering for this type of advice and support would be included in the complete site.

Discussion forums are also a popular choice for health websites (Blank & Adams-Blodnieks, 2003). However, a forum has not been included in the plan for this website. The major reason for this is that as a cancer treatment information site there is a responsibility to provide accurate and accepted information to users. A forum for patients could introduce less reliable information to users. A facility for asking questions and providing responses was included in the website design to address this particular user need.

Information sources

The US Food and Drug Administration database (http://www.fda.gov/) was used to find the accepted and general mechanisms of action of licensed cancer drugs. A selection of oncology textbooks was used to research the principles underlying the various treatment types. This information was supplemented using journal articles and websites (see appendix 2).

2. Conceptual design

2.1 Object modelling

The website was separated into sections. Different cancer treatments were divided according to their method of action and their presentation to patients. An introductory section about the biology of cancer was included for completeness, and a glossary section.

This led to the following six sections:

What is cancer?
Chemotherapy
Radiotherapy
Surgery
Biotherapy
Glossary

Several other important aspects were included within the site design: a frequently asked questions for each section; a news feed (containing recent developments in cancer treatments and news on clinical trials) on the homepage; links to other 'approved' websites (offering alternative services, such as support, references, cancer-specific sites, cancer centres, journals and newsletters, pain management); news and future pages for each treatment section to address potential developments for this treatment type.

2.2 Navigational Design

The information was split up into appropriate sections, which were then linked together. The aim was to create a logical flow of information for the user, to produce a helpful resource.

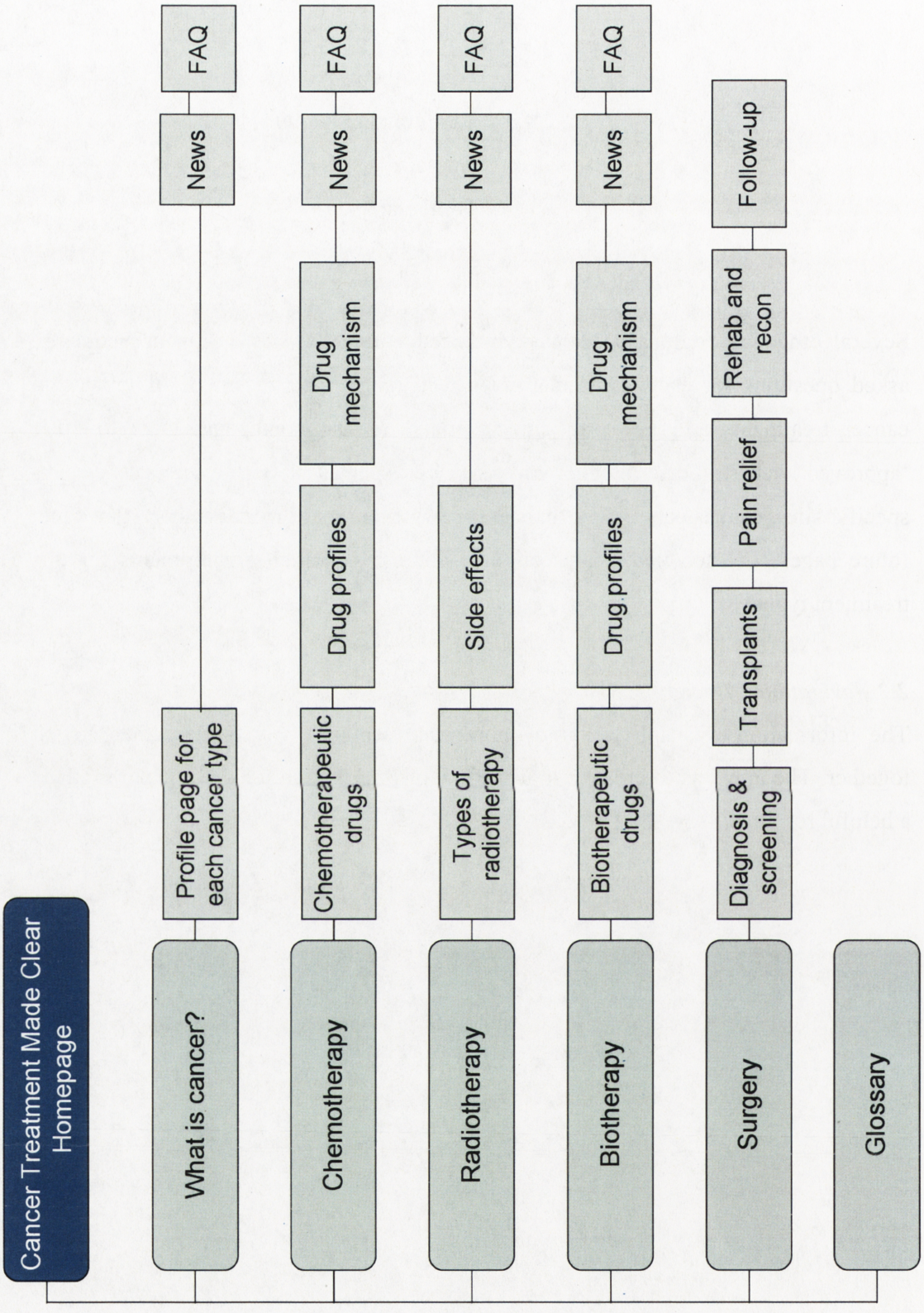

Figure 9: A graphical representation of the organisation of the proposed website

Homepage

The homepage was the first page to be developed. It has a short introduction to the site, but is mainly made up of links to other content.

It features a "breaking news" feed, which in the prototype web site is only a dummy version. In the finished version, this would be continuously updated with links to media releases. This aspect cannot be fully developed due to its dynamic nature.

The prototype homepage does not feature the links to other cancer websites that would appear on the finished version. These links were not developed because it is required that the other sites would provide a reciprocal service, linking their users back to this site for information about more technical treatment information.

The homepage design was based loosely around the front-page of a newspaper, a familiar and organised layout with which most users will be comfortable.

What is cancer?

The main 'what is cancer?' page was developed, and contains an overview of biological principles underlying the progression of cancer.

This section also contains profile pages of different cancer types. Two profiles were completed; one for chronic myelogenous leukaemia (CML), and one for gastrointestinal stromal tumours (GISTs). They were chosen as both of them are treated with the same drug. Cancer profile pages briefly address the cancer type and detail possible treatment options.

Chemotherapy	Radiotherapy	Biotherapy
The central page: 'what is chemotherapy?' contains an explanation of how chemotherapy combats cancer. The 'chemotherapeutic drugs' section provides drug profiles, one of which (hydroxyurea) was developed. The profiles detail the drug distributor, side effects, cancer types the drug is used for and the mechanism of action. The mechanisms of action of chemotherapeutic drug action are also addressed. These explanation pages are accessed through the 'chemotherapeutic drugs' section. The page explaining antimetabolite chemotherapeutics was developed.	The central page: 'what is radiotherapy?' explains the major principles of radiotherapy for cancer. The 'types of radiotherapy' section was also fully realised to detail the different methods of administration of radiation treatment. 'Side effects', a section dealing with the potential short and long-term effects of radiotherapy was developed. The radiotherapy 'news' section was the only one to be developed, and it contains some brief updates on new developments in radiotherapy.	The central page: 'what is biotherapy?' explains the underlying principles of biotherapy. The 'biotherapeutic drugs' section consists of search facilities within the five major biotherapeutic drugs types: monoclonal antibodies, hormone therapy, angiogenesis inhibitors, growth factors and immunotherapy. Each drug has a profile page (just as in the chemotherapy section). The drug chosen to focus on was Imatinib mesylate (Gleevec/Glivec). It is one of the best established biotherapeutic drugs, used in chronic myelogenous leukaemia (CML) and gastrointestinal stromal tumours (GISTs). Each drug profile page, users has links to pages explaining how the drug combats the cancer type. Pages explaining Imatinib action in CML and GISTs were developed.

Table 19: Proposed content of therapy sections of proposed website

Surgery

This section deals with the role played by surgery in cancer treatment. Pages include: 'surgery for cancer' (developed); 'diagnosis and screening' (developed); 'transplants' (developed); 'pain relief'; 'rehabilitation and reconstruction'; and 'follow-up'.

Glossary

The glossary section consists of a dictionary page of medical terminology. Medical terms used throughout the site were included in the development of this page.

Other web site elements

Each web page has a 'footer' banner containing links to other important site elements. Including a 'contact us' link, which would enable the user to make enquiries, either by email or by post. An 'about us' page, containing a brief description of the web site developers, and the aims and purposes of the site is also necessary. Links to pop-up windows containing: copyright details of the site and its information; a disclaimer explaining that the information presented on the site is not a substitute for medical consultation and should be discussed with their doctor; and a privacy statement explaining that the site abides by the data protection act, and any information users give will be kept confidential. Another important element linked to via the footer is the site map, which would show the layout of the entire site and allow users to find information quickly and easily. Finally, an RSS (Really Simple Syndication) feed function would be accessible from the footer. These web "feeds" or "channels" contain a summary of content from the web site and allow users to receive relevant information in an automated manner that is more convenient than users checking the site regularly.

The footer elements were not developed for the prototype website. The main reasons for this were time constraints and the prioritisation of more information-based pages.

Another aspect of the site that was planned but not realised is the frequently-asked-questions pages for each treatment section. This area was omitted due to the difficulties obtaining questions from users to answer.

3. Implementation design

The interface design was developed with consideration of the factors outlined in 'implementation design'.

Colour was used to aid navigation, with each section having a different banner colour.

Efforts were also made to preserve consistency throughout the site.

In terms of information presentation, all explanatory pages used graphics to illustrate the underlying biological principles. Two animations were used. Text was kept concise and technical language to the bare minimum. Any use of jargon was linked directly with a definition from the glossary.

To cater for older adults who may experience difficulties with sight, a font size of 13 pixels was used (it is recommended to use between 12-14 point), with dark grey text over a white background, which previous studies have shown older adults prefer (Nahm, Preece, Resnick, and Mills, 2004).

4. Implementation

Hardware

Computer: Apple PowerMac 12,1
512MB RAM
160 GB hard disk

Software

The website creation program Adobe Dreamweaver CS3 was used for building the website.

Graphical elements were created in Adobe Photoshop CS3.

Adobe Flash CS3 was used for generating animations.

Summary

This methodology section describes the way in which this website was planned, structured and created. A section from each area was developed to give the best possible impression of how the finished site would function as a collective, inter-linking whole. The focus of the planning was 'user-centred' in an attempt to provide answers to the questions the users may have. Efforts were also made to create a website that was intuitive and natural to use.

Chapter 4: The Website

A note about the website

As has been mentioned previously, the prototype website is not fully developed. This means that many of the links are not operational. To help navigate along the paths that have been developed, a map of the website has been included. Links between the various branches are not included on the map, but do exist and are fully functional.

For instructions of use see Appendix 1.

Figure 10: A map showing the developed areas of the prototype website

Chapter 5: Conclusions

The ever-increasing diversity of treatment options for cancer means that patient decision-making is becoming more and more important. This thesis attempts to address the deficits in patient understanding regarding these treatment alternatives by proposing and designing a treatment information website.

The three over-arching research questions that this thesis addresses are:

1. What evidence exists to support a web-based information resource?
2. What kind of information do cancer patients need about treatments?
3. How can cancer treatment information be presented on a web site?

The evidence exists to support the usefulness of a web-based cancer treatment information resource

Previous literature suggests that many cancer patients do not understand the purposes of the therapy chosen (Mackillop et al, 1988; Quirt et al, 1997). The continuing expansion of the range of available treatment options means that patient understanding is becoming more and more important to support informed decisions about their care. Treatment-specific patient education is required to bridge the communication gap.

Education not only facilitates informed-decision making but has also been shown to improve patient satisfaction, overall quality of care, and help reduce fear of cancer (Cohen & Britten, 2003; Steinberg, 2003; Berman & Wandersman, 1991). The positive outcomes of educating patients mean that an information resource about treatment options is desirable.

Current literature presents the Internet as an appropriate medium for conveying treatment information to patients. The accessibility and flexibility of the Internet as a medium means that it is already used widely by the public to research health care issues (Ball & Lillis, 2001; Ziebland et al, 2004; Ziebland, 2004). As the online community continues to grow and technology develops, the status of the Internet as a resource is only going to increase (Eng & Gustafson, 1999).

Critically, cancer patients are also expressing a desire for information online. Thirty per cent of cancer patients in the USA are thought to actively seek information about their condition online (Helft et al, 2003). This indicates that not only is patient education required, and the Internet the optimal tool, but the desired users (cancer patients) also recognise the importance of knowledge, and the capacity of the web to deliver information to them.

Cancer patients need more information about their treatment options

Once the Internet has been widely accepted as a suitable means for educating cancer patients, the type of information needed and desired must be established. Cancer patients appear to be eager for all aspects of possible information surrounding their disease: medical, emotional, social and financial (Rozmovits & Ziebland, 2004). However, medical information appears to be the most widely searched for online (Fox & Fallows, 2003). This suggests a perceived deficit in knowledge and understanding on the part of patients. However, the specific information needs of cancer patients are not really identified, and many aspects fall under the umbrella of "treatment information" which is used in the literature (Blank & Adams-Blodnieks, 2003). Treatment options and drug information do emerge as an expressed need in some studies but are not described in any great detail (Rosmovits & Ziebland, 2004; Salo et al, 2003; Helft et al, 2005; Ramos et al, 2004). This means that definitively isolating the information needs of patients regarding their treatment options is difficult.

Looking at the currently available treatment information online highlights some of the gaps in communication. Sites expressly catering to cancer patients (such as charitable/government sites and commercial health care sites) rarely attempt to explain how the various treatments work or give specific information about treatment performance in clinical trials. Whether this neglect is due to a genuine belief that information of this kind is not necessary or not desired is unclear. It may simply be a result of lack of time, resources and expertise in communicating more complex concepts to the lay person.

When trying to identify the information *needs* of cancer patients, although treatment information is a commonly recognised desire, the specifics are not clear. Further investigation of the aspects of treatment information patients want access to is

necessary. The lack of patient input in this thesis limits the effectiveness of the designed web site.

An aspect which must be considered when providing information about treatments to any patient, is the impact the information may have upon health care. Generally, patient education is regarded as a positive influence upon health care; associated with patient empowerment and improved delivery of health care (Ziebland, 2004; Sillence et al, 2007b; Ramos et al, 2004). However there are potential pitfalls to be aware of, including damage to the relationship between patient and their doctor (Murray et al, 2003; Ziebland, 2004). Cancer patients and physicians need online information that augments patient understanding and supports a more equal partnership in health care, allowing patients to make informed-decisions regarding their treatment options.

How can cancer treatment be presented in a web site?

Previous literature highlights the critical importance of user trust in health care web sites (Sillence et al, 2007b). When designing the prototype web site aspects that affect user trust were considered; a professional interface design was employed, efforts were made to make the site easy to use, clearly stated aims were made visible, technical language was avoided, and simple, clear, concise explanations were used with supporting graphics (Eysenbach & Kohler, 2002; Rozmovits & Ziebland, 2004; Sillence et al, 2007a).

Lessons were also learnt from current web sites. Lack of visual explanations for complex mechanisms is not only unhelpful but also excludes many with either lower reading abilities or who learn best visually. A strong focus on graphics and animations was therefore pursued.

Limitations

The major limitation of the prototype web site is the lack of evaluation. Without feedback it is impossible to assess the effectiveness of the site. Other limitations include the lack of patient involvement; ideally when designing a resource for a particular user group, consultation and involvement of members of that group should be used to ensure the right content is included, and that it is presented in the right way.

In terms of the technical aspects of the website, such as the diagrams, graphics and animations, they were completed without expert involvement. This means that they are not of professional standard. The US Food and Drug Administration was used as a guide to content, this means the website may not represent the drug availability of other countries. This could be addressed by including a code to show drug availability in different countries, for instance the Therapeutic Goods Administration for Australian users.

Finally, a collaborative effort to design and build this website would probably improve it. As the work of an individual, there is an inevitable bias towards that person's preferences in presentation, structure and content. However, all of these limitations are due to the unavoidable time constraints of the project.

Further work

Questions concerning the website that remain unanswered include:

Do cancer patients feel comfortable with the proposed website?
Is the information presented in a clear, logical manner?
Would cancer patients use a resource of this type?
Is there anything missing from the proposed site?

Further work that emerges from this study includes not only an evaluation of the proposed site, but also further study of the informational needs of cancer patients specifically focusing on treatment. This would help create a more tailored resource appropriate to the target audience.

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Appendices

Appendix 1: Instructions for use

The prototype website: cancer treatment made clear has been copied onto CD-ROM (700MB). To use the website insert the CD-ROM and open the 'cancer web' file. Find the 'home.html' and open with either the Firefox or Safari Internet browser. The site operates just as a normal website except it is not fully developed. Use the map (p.81) to navigate along the developed pathways and avoid dead-ends.

N.B. The website does work in Internet Explorer but because it was developed on a Macintosh using Firefox and Safari, it works much better in these browsers.

Appendix 2: Sources used for website content

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